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INTRODUCTION

As an increasing number of women at risk for ovarian cancer pursue risk-reducing surgery, they deserve research-based information on the quality of life implications of this option. In response to this vastly understudied area, our effort to prospectively study women who choose prophylactic surgery provides much-needed feedback for other women who seek counseling regarding cancer risk reduction strategies. A comparison of women undergoing surgery with a control group of those who opt not to pursue it allows a more rigorous scientific perspective to support clinical management.

Extension of the data collection period provided matched groups for final analysis. Here we report key findings that are now being incorporated into the clinical setting. A comprehensive decision-making resource for women considering risk-reducing surgery for ovarian cancer risk is in final draft format with publication expected shortly.

BODY

The following summarizes activities associated with each task in the Statement of Work.

Task 1: Creation of Participant Advisory Board

We have built strong networking relationships both internally and with the wider community. The draft manuscript for our decision-making resource is currently under review by 21 experts throughout the U.S. The perspective of these lay and professional advisors ensures a consensus of clinically relevant information. The manuscript incorporates study outcomes as well as patient focus group input.

Task 2: Selection of Survey Instruments

Survey instruments reported previously are summarized here.

1. The NSABP BCPT Quality of Life Questionnaire. This instrument was used by over 13,000 women in the Tamoxifen prevention trial. It includes the Medical Outcomes Study (MOS) 36-item short form, a generic measure of health-related QOL, the Center for Epidemiologic Studies-Depression Scale, used widely in community epidemiologic studies, the MOS sexual problems scale, and a 43-item symptom checklist of commonly reported physical and psychologic symptoms, as well as symptoms associated with the menopause, including the domains of vasomotor symptoms, vaginal dryness, sexual functioning, sleep disturbance and cognitive functioning. Sleep patterns and sleep quality may be disrupted by surgical menopause. This questionnaire is collected at all time points.
2. Post-Surgical Expectations Questionnaire. The NSABP BCPT Quality of Life Questionnaire has been modified to assess women's expectations of menopausal symptoms they anticipate experiencing following oophorectomy. It includes an open-ended response format as well as a Likert-type summary scale of symptoms. This questionnaire is only assessed at baseline, prior to surgery.
3. Fallowfield Sexual Activity Questionnaire (SAQ). This tool is a validated

measure for describing the sexual functioning of women in terms of activity, pleasure and discomfort. It was developed to investigate the impact of long-term Tamoxifen usage on the sexual functioning of women at high risk of developing breast cancer. This measure is collected at all time points.

4. Self Concept Scale. This 10-item scale assesses the participants' satisfaction with different areas of their body and their overall weight. Persons undergoing oophorectomy may experience an alteration in their perception of their body image, which may affect their psychosocial status and intimate relationships. This scale was developed by Dr. David Cella, (Director, Center on Outcomes Research and Education, Evanston Hospital) through his work with breast cancer patients. It is collected at all time points.
5. Medical/Dietary Supplement Survey. This survey elicits use of hormone replacement therapy, dietary supplements, micronutrients, as well as exercise, yoga, meditation, and other forms of coping strategies. The survey has been piloted among 48 women in the FRAP program for feasibility and ease of administration. Overall, we found that 89% of the women surveyed took some form of dietary supplement. It is collected at all time points.
6. Post-Surgery Satisfaction Questionnaire. Patients' levels of satisfaction with oophorectomy will be assessed using three items rated on a 5-point Likert-type scale. Scores from the three items will be combined to form a composite index of satisfaction. It is collected at all post-surgery time points.
7. Medical Outcomes Survey. This survey will capture information on new medical diagnoses, procedures, and screening exams at the 12-month follow-up time point. It is adapted from our current FRAP annual follow-up questionnaire.

Task 3: Development of a Recruitment Strategy

Enrollment ended 9/30/04. Final analysis includes matched groups with 38 in the surgery arm and 37 in the control arm. While total enrollment was less than the number originally proposed, it represents a majority of our women who pursued risk-reducing surgery decision-making during the study enrollment period.

Task 4: Creation of Data Entry Screens, Data Editing Program

This task is completed. A series of edit checks and quality assurance measures take place on a routine basis whenever data is entered into our bioinformatics system.

Task 5 & 6: Conduct Baseline & Follow-up Surveys

These tasks are completed.

Task 7: Data entry, data analysis

Several 12-month timepoint surveys were not data entered in time for the analysis reported here. A manuscript for publication will include these. Summary statistics are included in this report and more extensive analysis will be published.

Task 8: Report, manuscript preparation

The required application for ongoing review by the Research Review and IRB committees at Fox Chase Cancer Center was prepared and approved on 3/17/05. A comprehensive decision-making resource for women considering risk-reducing surgery for ovarian cancer risk is in final draft format with publication expected shortly. A study manuscript is in the process of preparation.

KEY RESEARCH ACCOMPLISHMENTS

- No significant differences in selected sample characteristics regarding median age, race, or education level. (See Table 1).
- The NSABP BCPT Quality of Life questionnaire is a compilation of four subscales that are analyzed and reported separately here. The subscale measuring depression, the CES-D contains 20 questions rated 0-3 with a higher score indicating more distress. The cutoff for clinical depression is ≥ 16 . The percentage of women in the surgery group scoring ≥ 16 ranged from 13.1 to 18.4% over the four time points; in the non-surgery group, the range was 13.5 to 27%. The ranges are consistent with those in general population studies (Ganz, 1995). At no time point was there a statistically significant difference in scores between the two groups. The summed scores were analyzed to test for a change in depression between baseline and one month within groups and between groups and no significant changes were detected.
- The 43-item symptom checklist subscale analysis (NSABP BCPT Quality of Life questionnaire) showed significant differences at one month between the surgery and control groups in the following measures: the surgery group had a higher percentage of sample experiencing hot flashes ($p=0.0001$), constipation ($p=0.018$), decrease in appetite ($p=0.008$), night sweats ($p=0.0058$), cold sweats ($p=0.028$), weight loss ($p=0.04$), and excitability ($p=0.04$). At six months, the surgery group had a higher percentage of sample reporting hot flashes ($p=0.003$), pain with intercourse ($p=0.029$), vaginal dryness ($p=0.002$), and forgetfulness ($p=0.019$), whereas the control group reported more menstrual cramps ($p=0.048$). At twelve months, the surgery group had a higher percentage of sample reporting difficulty concentrating ($p=0.048$), forgetfulness ($p=0.008$), and vaginal dryness ($p=0.005$). At twelve months the control group had more menstrual cramps ($p=0.00009$) and vaginal discharge ($p=0.017$). (See Table 2)
- From the symptom checklist subscale the 10 most commonly reported symptoms were determined by group and by combined groups. The ten most commonly reported symptoms at one month by all women in both groups combined and by group are reported in Table 3. Overall, general symptoms are common in both groups of women. Again, however, hot flashes and night sweats predominate in the surgery group.
- The MOS-SF-36 includes eight subscales of physical functioning, role functioning (physical), role functioning (emotional), social functioning, bodily pain, mental health, vitality and general health perceptions. Means of these subscales were calculated and compared between groups. The surgery group had more limitation of daily activities (physical functioning, $p=0.03$), more alteration in work or daily activities (role functioning, physical $p=0.0001$), and more interference in social functioning ($p=0.0036$). The surgery

group also had more bodily pain ($p=0.01$), when compared with the control group. Only bodily pain persisted in the surgery group at 12 months. (See Table 2).

- The Fallowfield SAQ was developed to measure the effect of tamoxifen use on the sexual activity of women at risk for breast cancer (Thirlaway & Fallowfield, 1996). The SAQ is analyzed by a pleasure score, pain score (discomfort during intercourse), and habit score (or how frequency of sexual activity compares with the woman's norm). There was no difference in percentage of women between groups engaging in sexual activity at baseline but at one month there was a significant decrease in frequency of sexual activity in the surgery group ($p=0.05$). The surgery group's increased pain during sexual activity reached statistical significance at baseline, 6 months and 12 months ($p=0.019$, $p=0.004$, $p=0.009$). Further the frequency of sexual activity was less than what was usual at one month in the surgery group ($p=0.0008$) (See Table 4).
- SAQ data was tested to assess whether the change from baseline to month 1 was significant or not for the two groups. The surgery group experienced a significant decrease in frequency of sexual activity from baseline to one month ($p=0.00024$). The surgery group experienced a larger decrease in frequency of sexual activity than the non-surgery arm ($p=0.00158$). The same pattern was seen when assessing change in habit score; the surgery group's decrease in frequency (compared to what was the norm) was significant from baseline to one month ($p=0.00049$). This decrease was larger than that of the non-surgery group between the two timepoints ($p=0.00072$). No significant difference was detected in changes of pleasure and pain scores from baseline at one month for both groups and between the two groups.
- The Self-Concept Scale is a well-established body image attitudes measure and has been used in studies with both cancer patients and healthy populations. It is a revised version of the Body Parts Satisfaction Scale [BPSS] (Petrie, Tripp & Harvey, 2002). There was no significant difference in self-concept at either baseline or one month between the surgery and control groups (See Table 5).
- Regarding post-surgery satisfaction, women reported extremely high satisfaction with their surgical decision and confidence in making the right decision.

REPORTABLE OUTCOMES

Table 1 Sample Characteristics		
	Surgery n = 38	Control n = 37
<u>Age (median)</u>	45.5 yrs	43 yrs
<u>Race</u>		
Caucasian	36 (94.7%)	35 (94.5%)
<u>Education</u>		
Some College	30 (81%)	28 (80%)
<u>Marital Status</u>		
Married	30 (81%)	24 (69%)
Never Married	4 (11%)	5 (14%)
Divorced	3 (8%)	6 (17%)
<u>BRCA Gene mutation status</u>		
Positive	13 (34%)	11 (30%)
Indeterminate	19 (50%)	14 (38%)
Not tested	6 (16%)	12 (32%)

Table 2 Quality of Life Measures

	Baseline		1 month		6 month		12 month	
	Surgery	Control	Surgery	Control	Surgery	Control	Surg	Cont
Everyday problems during the past 4 weeks	56%	29%	69%	22%	62.5%	22%	61%	40%
% reporting hot flashes		p=0.04		p=0.0002		p=0.003		
% reporting decrease in appetite	13%	5%	39%	9.6%	16%	11%	9.6%	None reported
% reporting constipation	23%	23%	48%	19%	36%	14%	25%	28%
% reporting vaginal discharge	36%	26%	28%	22%	12%	18%	6%	32%
% reporting vaginal dryness	45%	11%	34%	12%	56%	14%	53%	16%
% reporting cramps	23%	32%	15%	25%	9%	33%	0%	40%
% reporting weight loss	16%	8%	27%	6%	22%	7%	6%	4%
% reporting cold sweats	12%	5%	23%	3%	19%	7%	12%	8%
% reporting night sweats	42%	23%	58%	22%	40%	25%	41%	20%
% reporting excitability	21%	26%	28%	6%	22%	22%	29%	12%
% reporting difficulty concentrating	36%	44%	40%	41%	37%	29%	48%	20%
% reporting forgetfulness	50%	35%	54%	41%	65%	33%	64%	28%
Physical Functioning	90	82	72.8	82	85	86.8	84	85.6
Role Functioning (physical)	80.8	83.8	31	76.6	79	87.9	80.6	82
Social Functioning	89.2	85.6	62	78.6	89.9	88.4	82.6	84
Bodily Pain	70.6	64.8	49	63.8	70.7	76.3	61.9	70.8

Table 3: Ten Most Commonly Reported Symptoms at One Month			
Symptom	% Overall n = 75	% of Surgery Group n = 38	% Non-surgery Group n = 37
Unhappy with appearance of body	57%	55%	59%
Headaches	53%	47%	59%
General aches & pains	48%	55%	35%
Tendency to take naps; stay in bed	45%	55%	35%
Forgetfulness	43%	50%	35%
Hot flashes	43%	66%	---
Short temper	41%	45%	38%
Night sweats	37%	55%	---
Joint pain	36%	---	35%
Difficulty concentrating	35%	---	35%

Table 4 Sexual Activity Questionnaire								
	Baseline		One month		6 month		12 month	
	Surgery	Control	Surgery	Control	Surg	Cont	Surg	Cont
% engaging in sexual activity	76.4%	75.7%	51%	61%	74%	70%	73%	64%
Frequency of sexual activity score	1.5	1.4	2.1	1.6 p=0.05	1.6	1.6	1.7	1.5
Pleasure score	13.4	13.9	11.8	14.2	12.8	13.7	13	14.5
Pain score	4.5	3.3 p=0.01	4.6	3.2	5.2	3.2 p=0.004	4.8	3.1 p=0.009
Comparison of sexual frequency with what is normal for participant	2	2.2	2.6	2 p=0.0008	2.3	2.2	2.2	2.0

Table 5 Self Concept Scale								
	Baseline		One month		6 month		12 month	
	Surgery	Control	Surgery	Control	Surg	Cont	Surg	Cont
Satisfaction with body score	24.9	24.5	26.2	25.3	26.1	24.1	26.1	24.7
Importance of breast appearance	2.5	2.7	2.4	2.6	2.3	2.7	2.4	2.5
Self concept of weight	1.5	1.4	1.5	1.4	1.3	1.2	1.3	1.2

CONCLUSIONS

Final analysis of this prospective study compares quality of life variables between two groups of women at increased risk of ovarian cancer. Both groups considered risk-reducing oophorectomy; one proceeded with surgery and the other did not. The groups were matched in age, race, education, marital status and *BRCA* gene mutation testing status. Important findings from this analysis presented here show statistically significant short term differences between groups with the surgery group experiencing more hot flashes, night sweats, cold sweats, decrease in physical and social functioning and decrease in sexual activity frequency and pleasure. These changes are understandable given that the majority of women were premenopausal at the time of surgery. The abrupt drop in hormone levels after ovary removal accounts for the symptoms reported. Managing these menopausal symptoms is a key area of clinical intervention.

It is encouraging to see that despite the challenge of menopausal symptoms, women in the surgery group reported an extremely high level of satisfaction with and confidence in their decision. Also of note is there was no difference in self-concept between groups.

The differences in key areas of quality of life and sexual activity after surgery are already being incorporated into our counseling of women considering risk-reducing surgery. A decision-making resource guide for women considering risk-reducing surgery is in final draft and currently being reviewed by numerous lay and professional experts. This study's outcomes and the educational tool developed in conjunction with it will translate into direct usefulness for women seeking coping strategies for increased risk of ovarian cancer.

REFERENCES

- Ganz, P.A., Day, R., Ware, J.E., Redmond, C. & Fisher, B. (1995). Base-line quality-of-life assessment in the National Surgical Adjuvant Breast and Bowel Project Breast Cancer Prevention Trial. *Journal of the National Cancer Institute*, 87(18), 1372-1382.
- Petrie T.A., Tripp M.M., & Harvey P. (2002). Factorial and construct validity of the Body Parts Satisfaction Scale-Revised: An examination of minority and nonminority women. *Psychology of Women Quarterly* 26(3), 213-221.
- Thirlaway, K., Fallowfield, L., & Cuzick, J. (1996). The Sexual Activity Questionnaire: A measure of women's sexual functioning. *Quality of Life Research* 5, 81-90.

LIST OF PERSONNEL

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APPENDIX

Draft brochure: "Ovarian Cancer Risk-Reducing Surgery: A Decision-Making Resource"

Ovarian Cancer Risk-Reducing Surgery: A Decision-Making Resource

DRAFT

Pages

Introduction: Using This Resource

Section 1: Understanding Your Risk of Ovarian Cancer

Formal Risk Assessment

Mutations that Increase Risk

BRCA1 and BRCA2

HNPCC

Other Mutations Yet to Be Discovered

Interpreting Your Assessment Results

Section 2: Considering Risk-Reducing Surgery

Thinking about Your Own Situation

Why Do Women Choose Surgery?

It's a Proven Strategy

It Offers a Way of Taking Control

Why Do Women Not Choose Surgery?

Concern about Side Effects

It's Not the Right Time

A Strong Preference for Alternate Strategies

Perception of the Level of Risk

Some Tips for Decision-Making

Section 3: If You Want to Have Risk-Reducing Surgery: What You Need to Know

Before You Have Surgery

Understand All of the Advantages and Disadvantages

Choose a Surgeon

Make a Long-term Care Plan

Verify Health Insurance Coverage

What Surgery Involves

Types of Procedures

Why You Might Want, or Need, a Hysterectomy
Why You Might Not Want a Hysterectomy
Practical Planning before Surgery
Pre-surgical Procedures and Testing: What to Expect
Recovering from Surgery: What to Expect

After Surgery: Managing the Physical and Emotional Impact

Long-Term Considerations
Preventing Osteoporosis and Heart Disease
Cancer Screening

Section 4: If You Do Not Want to Have Surgery Now: What You Need to Know

Other Prevention Options
Taking Oral Contraceptives
Tubal Ligation

Close Surveillance by a Health Care Team

Participating in Research on Early Detection

Emotional Considerations

Section 5: Sexuality and Intimate Relationships after Risk-Reducing Surgery

Thinking about Sexuality

Get Educated and Plan Ahead
The Impact of Surgery on Your Sex Life
Managing Sexual Side Effects
Involve Your Partner
Ask for Help

Appendix: A Decision-Making Tool

Introduction: Using This Resource

If you are using this resource, you probably have some sense that you are at increased risk for ovarian cancer. Perhaps you have family members with the disease or you have had a formal risk assessment, which includes testing for genetic mutations that increase ovarian cancer risk. (If you haven't participated in a formal risk assessment, you should do so before making any decisions about risk-reducing surgery. See the next section, "Understanding Your Risk of Ovarian Cancer," for more information.)

Expert organizations such as the National Cancer Institute and the National Comprehensive Cancer Network traditionally recommended that high-risk women consider the option of having their ovaries and fallopian tubes removed by age 35, or as soon as childbearing is completed. Now, however, they qualify this recommendation by stressing that the decision should be made on a case-by-case basis, taking other factors into account. The surgery is technically called prophylactic bilateral salpingo-oophorectomy (which translates as "preventive removal of the ovaries and fallopian tubes on both sides"), although it is more commonly referred to as just prophylactic oophorectomy. Throughout this guide, we will refer to it simply as "risk-reducing surgery."

Research has shown that this surgery is a proven strategy for significantly reducing the risk of developing ovarian cancer. Currently, ovarian cancer is difficult to detect at an early stage — that is, before it has spread beyond the ovary and typically is still curable — even when a woman is being followed by her doctor with regular exams and testing. Studies have not been able to show that such close surveillance reduces a woman's risk of dying from ovarian cancer. Removal of the ovaries also can reduce the risk of breast cancer, which is reassuring to women who may be considering risk-reducing options for both breast and ovarian cancer.

While surgery has its benefits, it also entails some risks, many of which are not yet fully understood. Having your ovaries removed also means that your body will lose its source of the female hormones estrogen and progesterone. Therefore, depending on your age, this surgery could suddenly put you into menopause five, ten, 15, or even 20 years before you would have gone through it naturally. The medical community does not fully understand the long-term consequences of this "surgical menopause," although it almost certainly would increase your risk for osteoporosis (thinning of the bones) and potentially uncomfortable menopausal symptoms. These and other quality-of-life issues have to be considered before choosing risk-reducing surgery.

The Margaret Dyson Family Risk Assessment Program at Fox Chase Cancer Center has created this resource to help you learn about your options and use that knowledge to make a decision. In addition to discussing risk-reducing surgery, it reviews alternate strategies you can follow to try to reduce your risk of getting ovarian cancer or increase the chance that it will be detected in its earliest, most curable stage if it should develop. This resource also:

- explains the potential advantages and disadvantages of different courses of action
- discusses some recent research findings
- suggests questions that you can ask your health care team every step of the way
- lets you hear from women who have already been through the decision-making process, as well as from their partners.

At the end of the guide, you will find a decision-making tool that can help you sort through the options. You might find it helpful to share this information with loved ones or health care providers who are assisting you with your decision.

Remember, there is no absolute right decision — only a decision that's right for you. Be sure to take the time you need to sort through all of the issues and feel comfortable with your choice.

Remember, when considering surgery to reduce your risk of developing ovarian cancer, there is no absolute right decision – only a decision that's right for you.

Draft

Section 1: Understanding Your Risk of Ovarian Cancer

Formal Risk Assessment

To fully understand your risk of ovarian cancer, you need to go through a formal risk assessment, which involves working with a genetic counselor (a health professional specially trained to provide information and advice about inherited conditions) to chart your family history and consider genetic testing. To find such a professional, you can search the National Cancer Institute's online directory at www.cancer.gov/search/geneticsservices or call 1-800-4-CANCER, or you can check with cancer centers in your area.

The Risk Assessment Process

A formal risk assessment typically involves the following steps:

- Education about ovarian cancer and its risk factors
- Individualized counseling with a trained genetics professional
- Analysis of your family tree, showing the pattern of cancer in your family – who was affected and ages at which they were diagnosed
- Education about genetic testing options
- Genetic testing, if appropriate
- Discussion of the genetic test results
- Further counseling about risk-reduction options, if you are found to be high-risk.

Mutations that Increase Risk

Most women first begin considering risk-reducing surgery because a formal assessment has indicated they are at increased risk of ovarian cancer, usually based on a strong family history and/or a positive test result for an inherited genetic mutation that significantly increases that risk. These mutations involve the genes now commonly known as "BRCA1" and "BRCA2," or the genes related to a condition known as Hereditary Non-Polyposis Colon Cancer (HNPCC).

BRCA1 and BRCA2

In their normal form, the BRCA1 and BRCA2 genes help to prevent cancer by producing a protein that stops cells from growing out of control. When these genes are mutated, however, they cannot work properly, and this increases a woman's risk of developing both ovarian and breast cancer. If you and/or some of your relatives have a mutation in either of these genes, your family likely has experienced multiple cases of ovarian cancer alone or of both breast and ovarian cancer, typically at a younger age – often before age 50 or at least before menopause.

[Insert visual: a family tree typical of a family with a BRCA1 mutation]

Researchers are still learning more about how these mutations raise ovarian cancer risk. A recent article that looked at data from 22 different studies on this topic concluded that:

- Women with BRCA1 mutations have approximately a 40-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 18 percent to 54 percent.) Since a woman in the general population has just a two-percent chance of developing the disease (1 in 50), this means that a woman with a BRCA1 mutation is 20 times more likely to develop ovarian cancer.

- Women with BRCA2 mutations have approximately a 10-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 2.4 percent to 19 percent.)¹ This means that a woman with a BRCA2 mutation is five times more likely to develop ovarian cancer than a woman in the general population.

Also, women with the altered BRCA genes tend to develop ovarian cancer at a younger age. While the average age of onset in the general population is 62, mutation carriers are more likely to develop the disease in their mid-40s and 50s – a full ten to 15 years younger.

HNPCC Mutations

Another inherited syndrome known as HNPCC also raises ovarian cancer risk, although it is believed to account for less than two percent of hereditary ovarian cancer cases. HNPCC stands for Hereditary Non-polyposis Colon Cancer: family members who inherit HNPCC-related genetic mutations are at significantly increased risk for colon cancer, typically at an early age. These mutations also increase risk for cancer of the endometrium (the lining of the uterus), ovary, stomach, and other organs.

Estimates of HNPCC-related lifetime ovarian cancer risk vary, although one recent article estimates it at 12 percent.² This means that women with an HNPCC mutation are roughly six times more likely to develop ovarian cancer than women in the general population.

[Insert visual: bar graph comparing ovarian cancer risk for BRCA1, BRCA2, and HNPCC groups and the general population.]

Other Mutations Yet to Be Discovered

Even if you have a strong family history of ovarian cancer, you can test negative for the BRCA or HNPCC mutations. If these mutations have been confirmed in your relatives who had ovarian cancer, then your risk is considered the same as that of women in the general population. Clearly, you did not inherit the mutation that runs in your family.

However, if these mutations have *not* been confirmed in your family, you are still considered to be at higher risk of developing ovarian cancer than women in general. Researchers believe that there must be other inherited genetic mutations that can raise ovarian cancer risk, and perhaps one of these unknown mutations is responsible for the cancer in your family. Currently, this is an active area of investigation.

[Sidebar:]

My Experience

"It was not a hard decision for my family to get tested for the HNPCC syndrome. Each generation seemed to have a person who had died of colon cancer at a young age: my grandfather, my father's sister and brother, my father. The family history was very strong. I developed colon cancer at age 43.

I think everyone was just assuming that we had the syndrome. My sister basically said, 'It is what it is.' And that is how we all felt. We weren't going to get upset about it. My sister and I both tested positive. She shares the same attitude as I do: 'Well, now I know, and now I can do something about it.'" -Kelly

¹ Antoniou A, Pharoah PDP, Narod S, et. al. "Average risks of breast and ovarian cancer associated with BRCA1 or BRCA2 mutations detected in case series unselected for family history: A combined analysis of 22 studies." *American Journal of Human Genetics* 2003 May;72(5):1117-30.

² Brown GJ, St John DJ, Macrae FA, Aittomaki K. "Cancer risk in young women at risk of hereditary nonpolyposis colorectal cancer: implications for gynecologic surveillance." *Gynecologic Oncology* 2001 Mar; 80(3):346-9.

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"My mom was diagnosed with ovarian cancer in 1993. It was stage IIIc — pretty much a late diagnosis. She was one of a long line of people in our family to be diagnosed with and eventually die of cancer. It was within a few months of her diagnosis that I started thinking, 'Hey, this might be something that I have within me, too.'

Our history went back to a generation of people who do not have the benefits of the medical knowledge we have today. So there were many diagnoses of 'cancer of the female parts' and 'cancer of the stomach.' I think now that it was just that a lot of women had ovarian cancer-related ascites — buildup of fluid — and the doctor couldn't tell where the cancer had originated.

It turned out to that I have a BRCA2 mutation, just like my mom." -Lisa

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"I have a family history of breast and ovarian cancer. My mom was diagnosed with stage III ovarian cancer a little less than five years ago, at age 70. She also had a bout with breast cancer 25 years ago. In addition to that, she lost a sister in her 30s to breast cancer, and she has another sister who has now survived two bouts with breast cancer. So we knew we were good candidates for genetic testing. We called everyone — my brother, my older sister, my cousins, my mother's brothers — and told them they potentially had a genetic mutation they could have passed on to their children.

I think what scares me most is that my mom is very healthy woman who, as far back as I can remember, always walked five miles a day, ate extremely well, never smoked, rarely drank, and took some dietary supplements. The choices she has made have all been good. So that fact that *she* could get cancer from this risk factor of a mutated gene really concerns me, since I have it too." -Donna

Interpreting Your Assessment Results

A positive genetic test result or a strong family history of ovarian cancer (where no confirmed genetic mutation has been identified) significantly increases your risk of developing the disease over the course of your lifetime. This is of particular concern because ovarian cancer is difficult to detect early, making it a serious and potentially life-threatening disease.

At the same time, however, a positive result does not mean that you *definitely* will develop ovarian cancer. For example, if your lifetime risk of ovarian cancer is estimated at 40 percent because you have the BRCA1 mutation, there is still a 60-percent chance (better than one in two) that you will never develop ovarian cancer.

A positive genetic test result or strong family history significantly increases your risk of developing ovarian cancer, a hard-to-detect and potentially life-threatening disease, over the course of your lifetime. At the same time, however, this does not mean that you *definitely* will develop ovarian cancer.

This uncertainty may make it difficult for you to determine how you wish to act on the information. You have been diagnosed not with a disease, but with a lifetime risk of developing a disease. There is not yet a well-defined standard of care for women in this situation. Therefore, as you consider the advantages and disadvantages of the courses of action discussed in this guide, you also need to think about how much risk you can tolerate as you go about your daily life. This is a truly individual preference.

If necessary, go back to your genetic counselor for more in-depth discussion of what your positive test result and family history indicate about your lifetime risk of ovarian cancer. If you have not already done so, you should consider meeting with a gynecologic oncologist, a physician who specializes in diagnosing and treating cancers of the female reproductive system. You can ask your primary care doctor or gynecologist for a recommendation.

For More Information on Genetic Mutations and Cancer Risk

American Board of Genetic Counseling

(301) 571-1825

www.abcg.net

Prepares and administers examinations to certify individuals who provide services in the medical genetics specialty of genetic counseling and accredits training programs in the field. Also maintains a directory of board-certified professionals.

FORCE: Facing Our Risk of Cancer Empowered

(954) 255-8732

www.facingourrisk.org

A nonprofit organization for women who are at high risk of breast and ovarian cancer due to their family history and genetic status, and for members of families in which a *BRCA* mutation may be present.

Myriad Genetic Laboratories

(800) 469-7423

www.myriad.com

Myriad Genetics, Inc. handles testing for mutations that can increase cancer risk. Free educational materials are available.

National Cancer Institute

Cancer Genetics Services Directory

1-800-4-CANCER

www.cancer.gov/search/genetics_services/

A directory of individuals who provide services related to cancer genetics (cancer risk assessment, genetic counseling, genetic susceptibility testing, and others). The NCI also offers a free brochure titled "Understanding Gene Testing."

National Society of Genetic Counselors

(610) 872-7608

www.ngsc.org

Offers a searchable database of genetic counselors and other information about the genetic counseling profession.

For More Information on Ovarian Cancer

American Cancer Society

1-800-ACS-2345

www.cancer.org

Association of Cancer Online Resources

www.acor.org

Best-known for hosting a number of electronic mailing lists designed to provide support and information for people who have or are concerned about cancer — including the Ovarian Problems Discussion List.

Cancer Care

1-800-813-HOPE or (212) 302-2400
info@cancercare.org
www.cancercare.org

Johns Hopkins Ovarian Cancer Information
www.ovariancancer.jhmi.edu

National Cancer Institute
1-800-4-CANCER
www.cancer.gov

National Ovarian Cancer Coalition
1-888-OVARIAN or (561) 393-0005
NOCC@ovarian.org
www.ovarian.org

Ovarian Cancer National Alliance
(202) 331-1332
ocna@ovariancancer.org
www.ovariancancer.org

QUESTIONS TO ASK . . . After a Formal Risk Assessment

These questions may help you when talking with your physician, nurse, or genetic counselor:

1. What are my test results? What are the chances of a false-positive or false-negative result?
2. Based on the specific mutation I have, combined with my family history, how significantly do you believe my risk for ovarian cancer is increased over that of the general population?
3. If I tested negative for a mutation but have a strong family history where no mutation has been confirmed, what would you estimate my risk of ovarian cancer is?
4. What course or courses of action do you usually suggest for women in my situation? Would you be willing and/or able to counsel me on my range of options, or would you rather refer me to someone who can?

5. I feel that I need extra support in dealing with this positive test result. Do you know of any counselors, social workers, or psychiatrists who specialize in working with individuals in my situation?
6. Is there a hospital or cancer center nearby that has a program for high-risk women that you would recommend (if you are not already enrolled in one)?
7. Should my other family members get tested?

Draft

Section 2: Considering Risk-Reducing Surgery

As you begin to consider risk-reducing surgery, you will quickly discover that cancer experts and organizations vary in how definitive their recommendations are. This variation reflects the larger sense of uncertainty about the long-term impact of removing a pre-menopausal woman's ovaries – and her body's source of estrogen and progesterone – on her quality of life and other aspects of her health *besides* cancer risk.

For example, the Gilda Radner Familial Cancer Registry at Roswell Park Cancer Institute in Buffalo, NY, recommends that all women with a family history of ovarian cancer in two or more first- or second-degree relatives undergo risk-reducing surgery. But guidelines issued by The National Comprehensive Cancer Network (NCCN), an alliance of 19 leading cancer centers, suggest a more individualized approach. They note that women at high-risk for ovarian cancer because of a genetic mutation or strong family history should consider the surgery on a “case-by-case basis, including discussion of reproductive desires, extent of cancer risk, degree of protection for breast and ovarian cancer, and management of menopausal symptoms and related medical issues.”

Thus, this decision is not a simple one. It requires careful consideration of the potential advantages and disadvantages of risk-reducing surgery in relation to your situation.

For More Information

National Comprehensive Cancer Network

1-888-909-NCCN

www.nccn.org

Follow the link to the NCCN Clinical Practice Guidelines in Oncology to find the guideline titled *Genetic/Familial High-Risk Assessment: Breast and Ovarian*, which includes information on options for high-risk women.

Thinking about Your Own Situation

As you consider the potential advantages and disadvantages of surgery, you need to consider the particulars of your own situation, such as:

- **Age and menopausal status:** If you are younger and potentially many years away from menopause, you may feel more strongly about avoiding surgery – and the menopausal symptoms it brings on – than if you are in your 40s or 50s and closer to menopause, or already experiencing it.
- **Desire to have children:** If you definitely want to or think you may want to have children, you should delay surgery for the time being.
- **The particular mutation you have:** As already noted, the BRCA1 mutation has been found to increase ovarian cancer risk to a greater degree than BRCA2 or HNPCC mutations. This may bear some influence on your decision, especially in relation to your family history (see next item).
- **The particulars of your family history:** Every family pattern is a little bit different. If numerous women in your family developed ovarian cancer in their 40s or 50s, you may be more

concerned about your risk than if there are one or two relatives who developed it at a later age, or if all of the affected women in your family had breast cancer.

- **Your tolerance for being “high-risk”:** Individuals vary in how they react to the knowledge that they are at higher-than-average risk for ovarian cancer. If this knowledge causes you to feel a constant sense of anxiety or worry, then risk-reducing surgery may be the best choice for you, despite its drawbacks. On the other hand, if you are more concerned about surgery’s impact on your quality of life than about your elevated risk for ovarian cancer, surgery may not be the best choice for you right now.

Also, you should know that, while surgery is the only proven tool for reducing ovarian cancer risk significantly, it is not a perfect solution. A small number of women who undergo risk-reducing surgery still go on to develop a form of cancer closely related to ovarian cancer, known as primary peritoneal carcinoma. This cancer originates in the peritoneum, which is the membrane that lines the walls of the both the ovaries and the pelvic cavity.

The decision-making tool at the end of this guide will help you to weigh all of these factors.

Women vary in how they react to the knowledge that they are at higher-than-average risk for ovarian cancer. If this knowledge causes you to feel a constant sense of anxiety or worry, then risk-reducing surgery may be the best choice for you. If you’re more concerned about the potential impact of surgery on your quality of life, then it may not be the best choice for you.

[Sidebar:]

My Experience

“I had the testing for the BRCA1 and BRCA2 mutations and it came back positive. At around the same time, my mom died of ovarian cancer. That was what really prompted me to look into risk-reducing surgery — plus the fact that I knew there was a lack of reliable testing to catch anything that might be going on early. Also, what made it easier for me was that, age 47, I was well into perimenopause, so the thought of becoming menopausal was almost a relief.” -Sarah

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“Because I was still in my late 20s/early 30s when I found out I was high-risk, I thought about risk-reducing surgery for a time later in my life — maybe mid- to late 40s. I knew that the surgery would bring on menopause. But even more important, I wanted to have children — I had my first at 33 — and I delayed anything because of that.

I still might consider surgery down the road. I am 42 now, and in my last conversation with my doctor, I was told that you should look at a family member who had ovarian cancer and subtract ten years from their age at diagnosis and view that as your window for really needing to be vigilant. My grandmother passed away from ovarian cancer at 52. So I am starting to think more seriously about surgery.” -Rose

Why Do Women Choose Surgery?

Ovarian cancer is a serious disease that tends to be diagnosed at a later stage — that is, after it has already spread beyond the ovaries — when it is difficult to cure. The ovaries’ location deep within the body makes it challenging for imaging tests and physical exams to diagnose early-stage tumors. There is a blood test for a protein called CA-125 that is often elevated when a woman has ovarian cancer. However, the test is not completely reliable: many women with early-stage ovarian cancers have a normal CA-125 result.

When women choose to have their ovaries and fallopian tubes removed, often this is because it is a proven strategy for significantly reducing their risk of developing ovarian cancer in the first place – and breast cancer as well. It also helps them feel as if they are doing all they can to take control of their situation, both for themselves and their loved ones.

It's a Proven Strategy

Over the past several years, a number of studies have shown that surgery reduces ovarian cancer risk. Generally, these studies have compared high-risk women who had the surgery with those who chose close surveillance by their doctors (frequent exams and testing) instead. For example:

- One study used registries of BRCA-mutation-positive women to identify 259 women who had undergone risk-reducing surgery and 292 matched controls who chose close surveillance instead, and then followed them for at least eight years. Only two women in the surgery group went on to develop peritoneal carcinoma (a form of cancer closely related to ovarian cancer), while 58 women in the non-surgery group received a diagnosis of ovarian cancer. Researchers concluded that the surgery reduced risk for ovarian cancer by 95 percent. They also found that the surgery significantly reduced breast cancer risk.³
- Another study followed 170 mutation-positive women for a mean time of just over two years. Of the 98 women who had risk-reducing surgery, one developed peritoneal cancer and three developed breast cancer. Among the 72 women who chose close surveillance over surgery, five were diagnosed with ovarian or peritoneal cancer, and eight with breast cancer.⁴
- A study that compared 43 women with BRCA1 mutations who underwent risk-reducing surgery with 79 mutation carriers who did not found a significant reduction in risk of for breast cancer in the former group – a nearly 50 percent reduction.⁵

Furthermore, in the first two studies mentioned above, several women who underwent risk-reducing surgery – three in the first group, and six in the second – were found to have early-stage ovarian cancers at the time of surgery.

Many women are convinced by these and other studies' conclusion that risk-reducing surgery offers a clear advantage over surveillance.

It Offers a Way of Taking Control

Many women choose risk-reducing surgery because it offers a way of taking control of their situation, both for their own sake and the sake of their loved ones. They see it as the best strategy for alleviating their anxiety about developing ovarian cancer and making sure that they will be there for their families over the long term.

Often, women in high-risk families have watched their mothers, sisters, aunts, or other relatives go through the difficult experience of being diagnosed with and treated for ovarian cancer. Some feel a strong need to take whatever action is necessary to avoid going through the same experience. For many women, the desire to have surgery increases as they reach the age at which their relatives developed ovarian cancer.

³ Rebbeck TR, Lynch HT, Neuhausen SL, et al. "Prophylactic oophorectomy in carriers of BRCA1 or BRCA2 mutations." *New England Journal of Medicine* 2002 May 23; 346(21):1616-22.

⁴ Kauff ND, et. al. "Risk-reducing salpingo-oophorectomy in women with a BRCA1 or BRCA2 mutation." *New England Journal of Medicine* 2002 May 23; 346(21):1609-15.

⁵ Rebbeck TR, et.al. "Breast cancer risk after bilateral prophylactic oophorectomy in BRCA1 mutation carriers." *Journal of the National Cancer Institute* 1999 Sep 1; 91(17):1475-9.

Many women choose to undergo surgery because it is a proven strategy for significantly reducing their risk of developing ovarian cancer in the first place – and breast cancer as well. Over the past several years, a number of different studies have confirmed this benefit.

[Sidebar:]

My Experience

"I had had breast cancer already. And subsequent to that, I underwent genetic testing, because I'm the fifth woman in three generations to have breast cancer and I also had an aunt who had ovarian cancer. When my test came back positive for the mutations – one on BRCA1 and one on BRCA2 – I knew what the probability was that I would develop ovarian cancer. I thought to myself, 'I've had my kids. These are optional organs at this point in my life.'" -Theresa

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"Even before I had genetic testing, I was considering prophylactic surgery for ovarian cancer. I decided that when I went through menopause, I would go ahead and do it. I knew that my cancer risk would increase anyway with age. But then I had a transvaginal ultrasound that showed an ovarian cyst, which raised the possibility of ovarian cancer. At that point, I decided to have my ovaries out right away, rather than wait it out and see if the cyst resolved. As it turned out, my ovaries were healthy.

I knew that the disadvantage of having the surgery would be going through menopause at 48. The advantage would be that I could reduce my risk drastically. I felt from the beginning that the reduction in risk would outweigh any side effects or impact on my life." -Kelly

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"I had my surgery in early 2002, within a month after it was recommended to me. I had been waiting for my doctor to make a recommendation one way or the other. My dad is a pediatrician who worked in a teaching hospital, so I grew up around medical research and had utter faith in it. And the studies had definitely proven you can reduce your risk of cancer by taking this action, and I was ready to do it. I was 38 at the time. I also had had some problems with heavy bleeding, so I was ready to have those organs out.

I guess I was determined to avoid the path that my ancestors had lain before me: many had died of cancer. My husband was all for it. He did not want to see me go through what my mom had gone through. I had been my mom's primary caregiver so I really saw ovarian cancer up close and personal, and I did not want to go there." -Lisa

Why Do Women Not Choose Surgery?

Even though risk-reducing surgery is the best preventive tool that physicians have to offer high-risk women, some choose not to have surgery right away, for a variety of reasons. This section explains the most common.

Concern about Side Effects

When a pre-menopausal woman has her ovaries removed, her estrogen level drops suddenly instead of gradually, as it would if menopause occurred naturally. As a result, she is likely to experience intense menopausal symptoms. The most common are hot flashes, night sweats, vaginal dryness and irritation, and a diminished sex drive, although women have reported a wide range of other physical symptoms: joint and muscle pain, fatigue, chest pain, muscle spasms, insomnia, recurrent urinary tract and yeast infections, urinary incontinence, and heart palpitations. Women also can experience emotional effects such as anxiety, depression, and mood swings.

For women who have already gone through menopause naturally, losing the ovaries is typically less difficult than it is for younger women, both physically and emotionally. The ovaries already have

stopped producing their usual level of estrogen and fertility is no longer an issue. Since the ovaries do produce small amounts of estrogen and other hormones after menopause, however, there may be some side effects.

In short, the nature and intensity of symptoms vary from woman to woman, but there almost certainly will be some impact on quality of life. In the past, many physicians would have automatically prescribed hormone replacement therapy (HRT) to alleviate these symptoms. However, a number of recent studies have raised new concerns about the safety of HRT, particularly for women who are considered to be at high risk of ovarian and breast cancer (see section 3 for more information about these studies). Some physicians believe that short-term use of HRT is still safe, while others disagree and steer women away from it. There are some non-hormonal approaches to managing surgical menopause, but none has yet proven as effective as HRT. This reality can sway some high-risk women — particularly those who are potentially many years away from menopause — to decide against surgery, despite its benefits in terms of ovarian cancer risk reduction.

The loss of estrogen has been found to increase a woman's risk for osteoporosis (thinning of the bones). Also, physicians do not yet have a complete understanding of how the loss of estrogen might impact heart health, mental functioning, memory, and other aspects of women's health.

When a pre-menopausal woman has her ovaries removed to reduce ovarian cancer risk, her estrogen level drops suddenly instead of gradually, as it would if menopause occurred naturally. Physicians are not yet sure about the long-term health effects of this "surgical menopause," nor are they certain about the best ways to help women deal with its symptoms safely.

It's Not the Right Time

Timing is often a key factor in a woman's decision not to have surgery. Obviously, if she still wants to have children, she should choose to delay surgery. But even women who do not want children or are finished having them decide to forgo surgery because it is not the right time in their lives to take this step. Surgery can be disruptive, both in terms of the time needed to have the procedure and recover, as well as in its impact on general well-being. Women with particularly demanding jobs, young children at home, or other family responsibilities may not feel they are ready for this. Others may feel as if they are too young to deal with the symptoms of surgical menopause and its potential sexual side effects, particularly if they are in an enjoyable marriage or other intimate relationship, or they are dating.

At least for now, these women are willing to cope with the knowledge that they are high-risk rather than cope with the surgery and its potential side effects.

A Strong Preference for Alternate Strategies

There are other strategies women can follow to reduce their risk of ovarian cancer, or at least try to catch it at an early stage if it does develop. Although none of these has proven as effective as surgery, they come with fewer physical side effects, if any. Their main drawback is that they may fail to allay a woman's anxiety about getting ovarian cancer as much as surgery does. Nevertheless, some women see them as a way of taking action without having to go so far as to have their ovaries and fallopian tubes removed.

Examples of these strategies include close surveillance (regular exams and testing by a physician) and oral contraceptive use. Some women decide to enroll in clinical trials that are evaluating new early detection methods for ovarian cancer. There have been some promising breakthroughs in the search for a more reliable blood test that could detect ovarian cancer at its earliest, most curable stage, although more research is needed before such a test will become commercially available. All of these are discussed in the later section "If You Do Not Want to Have Surgery Now: What You Need to Know."

Perception of the Level of Risk

Individual women react differently to the knowledge that they are considered “high-risk” for developing ovarian cancer. For example, there are different ways of looking at the level of risk conferred by BRCA1 and BRCA2 mutations.

Research suggests that a woman with a BRCA1 mutation has roughly a 40-percent lifetime risk of developing ovarian cancer. One woman might hear this and reason that her risk is more than 20 times that of an average woman in the general population, who has a two-percent lifetime risk – a drastic increase for a serious and potentially fatal disease. As a result, she may be more likely to choose surgery.

However, another woman might hear the same information and conclude that she still has a 60-percent chance of *never* developing ovarian cancer. She would be less likely to choose risk-reducing surgery, reasoning that she does not want to have surgery for something that may never happen. Or she may choose to delay surgery until she gets older and closer to menopause, since all women’s risk of ovarian cancer increases with age.

A woman’s perception of her level of risk also can be influenced by her family history. Even if she has a BRCA mutation or one connected with HNPCC, she may be less concerned about ovarian cancer risk if all of her relatives had other cancer diagnoses, such as breast and colorectal. Her perception of risk also may depend on how old her relatives were when they developed ovarian cancer. For example, if a woman is in her late 30s, and all of the ovarian cancer cases in her family occurred at age 45 or older, she may be more likely to decide not to have surgery right away. The same might be true of a woman in her early 40s whose relatives were diagnosed in their late 40s or early 50s.

[Sidebar:]

My Experience

“At first I was very clear in my mind that, if I tested positive for a mutation, I was going to have risk-reducing surgery. But I was clear for the wrong reasons. My mother’s bout with ovarian cancer was fresh in my mind. And it is extremely hard to watch someone you love go through something so difficult. So my thought was, Why wouldn’t I get an oophorectomy? How could I not get one? And then I thought, if I am going to do that, shouldn’t I get a mastectomy?

Then I began to really struggle with the prospect of completely altering my body – physically, emotionally, everything. I did not feel I had enough information on the quality-of-life issues that I might face as a result of risk-reducing surgery. I was young – just 40 years old – and I was going to put myself into surgical menopause, which has lots of other health risks and issues associated with it. It also can be extremely difficult to manage from a relationship perspective. All of this had to go into my decision-making. I am now 42, and I am keeping my ovaries and keeping my breasts, at least for the time being.” -Donna

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“Since I am finished having children, my biggest issue with the surgery now is being launched right into menopause. I feel it will be best to try to do it later, as close to the time of natural menopause as possible. ‘Later’ could be a year, could be two years, I don’t think it is going to be that far out. I have already experienced some perimenopausal symptoms. My husband and I have started the serious conversations.

Certainly I would like to lower my lifetime risk, if I can, and be here longer for my kids and my husband. But I will need to time the surgery so that it’s least disruptive. I am working full-time, my husband works and travels sometimes, the kids are in school. It may be that I decide to do it over a summer rather than a school year, which is a less challenging in terms of schedules.” -Rose

Some Tips for Decision-Making

The remainder of this guide will help you better understand the potential advantages and disadvantages of risk-reducing surgery. It ends with a decision-making tool that will help you put down your thoughts in writing. We offer these additional tips as well:

- **Take your time.** Don't feel as if you have to make a decision right away, and don't feel pressured. You need to give yourself time to consider all of the pros and cons of various courses of action.
- **Realize that making this decision is a process:** Even if you decide not to have risk-reducing surgery right now, you will need to reconsider your decision over time. Changes in your own health or your family history or new research findings may affect your decision over the long-term.
- **Get help:** You cannot make this decision alone. In addition to consulting with doctors, nurses, researchers, and/or genetic counselors who specialize in working with high-risk women, you may find it helpful to talk to other women who have been through the decision-making process. Be sure to involve trusted family members or friends as well; their help can be invaluable in sorting through the information.
- **Do your homework:** Certainly, reading this guide is a start, but keep in mind that new research studies can change current medical thinking. You may wish to do research on your own, or at least make sure you have access to a health care team that can keep you up to date on the latest medical research.

[Sidebar:

My Experience

"Talking to other women is helpful. I went to a focus group of high-risk women, some who had the surgery and some who didn't. I gathered a lot from listening to women who had had the surgery — what was good for them about it, what were the negatives. It was useful to hear the real-life negatives, not just read about them on paper.

I'd also recommend paying attention to the research. I think the only way you can have comfort in what you are doing is to know what is going on in the medical community. It is better to be armed with information and know ahead of time what could happen.

Finally, I would recommend having a spouse or family member or friend you can talk this decision over with. No matter who you are, it is always better to have someone to bounce your ideas and thoughts off of. Somebody who is not living through the shock of knowing that they have this genetic mutation can perhaps be more objective and help you straighten it out in your mind, and think about what is the best path to take. I wouldn't go it alone." -Rose

§

"I wish I had taken more time to make my decision to have surgery. In a manner totally unlike myself, I did not get on the Internet and start researching advantages and disadvantages. I didn't talk to anyone who had been through it. Had I done my normal course of research, study, and thinking, I might have made a different decision, given how much the surgery has impacted my quality of life.

I think it's important for women considering this procedure to know that they are absolute pioneers. Think of how differently the same medication can affect individual patients. The surgery can help you avoid cancer, but it also might change your life in ways you don't like or don't expect. You have to get all of the facts." -Lisa

§

"I look at making this decision as a process. For now, at 42, I have decided not to have risk-reducing surgery, but I know I will have to evaluate my decision as I get older. I think I take care of myself, and make good choices about how I live my life, and I am not afraid I am making the wrong decision. I do not want to make a decision based on fear.

I have looked for research that has been done on women who have had oophorectomies, and quite frankly there is not a lot out there, because it is so new. I did talk to a number of physicians who are now performing studies on these women's quality of life. But for now the information seems incomplete." -Donna

The Partner's Experience

"I was there to give my wife emotional support, and to be someone she could bounce ideas off of. I'm not very well-acquainted with medical terms; in fact, I get a little uneasy in the doctor's office. So she spared me a lot of the details, but I was there for moral support. And whatever she decided was going to be just fine with me." -Joe

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"My wife was certainly very proactive about researching and understanding the issues herself, and understood a lot better than I did. But I felt like this was a decision we made together. The key for us was when her physician came out and said this was the best thing to do. We decided to go in and do it." -Mark

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"My involvement was at all levels: research, reading, and listening. It helped that I have a fairly good science background. I wanted to make sure that she understood the technical aspects of what she was being told. I think it's easy to jump to conclusions about the information you're given, especially when you're feeling anxious. So I think my role was simply to try to get the facts straight." -Connie

SUMMARY | Reasons Women Do or Do Not Choose Risk-Reducing Surgery

Why Some Choose It

- It is a proven strategy for reducing ovarian cancer risk.
- It is a way of taking control, alleviating anxiety, and reassuring oneself and one's family.

Why Some Do Not Choose It

- They are concerned about potential side effects.
- It's not the right time in their lives.
- They have a strong preference for other risk-reduction and screening strategies.
- For right now, they do not feel that their risk of ovarian cancer justifies going through with surgery.

QUESTIONS TO ASK . . . When Considering Risk-Reducing Surgery

These questions may help you when talking with your health care team:

1. Based on my age, family history, and genetic test results, do you believe I am a good candidate for risk-reducing surgery? What do you usually recommend for women in my situation?

2. *If you are working with a gynecologist . . .* Do you have experience performing risk-reducing surgery? Would it be better for me to have the surgery done by a gynecologic oncologist (a physician with special training in diagnosing and treating gynecologic cancers)? (See the next section, "If You Decide to Have Risk-Reducing Surgery," for a more complete discussion of this issue.)
3. If you do perform the surgery, would you manage my follow-up care, or would you need to refer me to someone else?
4. What kinds of side effects have your patients experienced after surgery? How did you help them manage those side effects?
5. Do you think any of your patients would be willing to speak with me about their experience?
6. I am concerned about dealing with surgical menopause, especially given the controversy over hormone replacement therapy. How do you feel about the use of HRT, and what are the other options available for dealing with surgical menopause?
7. If I decide not to have surgery or at least delay it for the time being, what other strategies would you recommend for me? How would you monitor my care?
8. Is there anything else I should consider as I make this decision?

Section 3: If You Want to Have Risk-Reducing Surgery: What You Need to Know

If you feel that risk-reducing surgery is the right choice for you, your next step is to educate yourself about the procedure itself, the recovery time, potential short- and long-term consequences, and necessary follow-up care. This section is designed to help you learn more about what you can do before and after surgery to ensure you have the best possible experience. Also see Section 5, which focuses exclusively on the issues of sexuality and intimate relationships after risk-reducing surgery.

Before You Have Surgery

Risk-reducing surgery has clear advantages and disadvantages, many of which we have already discussed. It is important for you to understand all of them before moving ahead with the procedure. You also need to find a physician (or physicians) who will perform the surgery and manage all aspects of your follow-up care, which should include helping you to cope with side effects. In speaking with women who have undergone risk-reducing surgery, we have found that many wished they had gone into surgery with a better understanding of the possible consequences and ways they could be managed.

Understand All of the Advantages and Disadvantages

The previous section, "Considering Risk-Reducing Surgery," discussed surgery's major advantages: significant ovarian cancer risk reduction, some reduction in breast cancer risk, alleviation of anxiety, and a sense of control. It also discussed disadvantages such as surgical menopause and possible impact on quality of life. There are some other important advantages and disadvantages to consider.

Advantages

- **Availability of minimally invasive surgery:** Most risk-reducing surgeries can now be done through several small incisions in the pelvis, using a specialized instrument called a laparoscope. This lighted instrument has a fiber optic camera that allows the surgeon to visualize the pelvic cavity and operate on it without having to make a large incision in your abdomen. Laparoscopic surgery is still a major procedure and it does require some time to recover. However, it tends to involve fewer complications, shorter recovery time, and less scarring than abdominal surgery. (Some women need to or wish to have more extensive surgery, however, and this will be discussed in the next section, "What Surgery Involves.")
- **Cessation of monthly periods:** Some women, particularly those who have had difficult monthly periods with many symptoms, are relieved to have their menstrual cycles come to an end.

Disadvantages

The major disadvantage is surgical menopause, which will be discussed in more detail later in this section. There are some other important disadvantages to be considered:

- **A small remaining risk of cancer:** Surgery cannot completely eliminate the risk of developing an ovarian-cancer-like illness. Even after you have your ovaries and fallopian tubes removed, you still will have a small risk of developing a disease called primary peritoneal cancer. This form of cancer originates in the peritoneum, the membrane that lines the ovaries and pelvic cavity, and it looks and behaves very much like a stage III ovarian cancer. It also is very difficult to detect early.

Over the past couple of decades, a number of studies have followed women after risk-reducing surgery and documented this risk. Individual studies have found that anywhere from two percent to 10 percent of women go on to develop primary peritoneal carcinoma. Although more research is certainly needed, it is clear that this risk, while very small, is real.

Primary peritoneal cancer requires the same kinds of treatment as ovarian cancer, such as surgery and chemotherapy.

- **Continuing need for surveillance by a physician:** Even after risk-reducing surgery, you will need to be followed closely by a physician, mainly because of the risk of primary peritoneal cancer. And of course, you will need to start or continue routine surveillance for breast, colon, and other cancers.

You may be disappointed to learn that surgery is not always a perfect solution. However, keep in mind that the reduction in your ovarian cancer risk certainly will be much greater than your risk of ever developing primary peritoneal carcinoma.

Risk-reducing surgery can significantly allay your anxiety about developing ovarian cancer. You still need to be followed closely by your doctor, however, because there is a small risk of developing an ovarian-cancer-like illness called primary peritoneal cancer.

SUMMARY | Advantages and Disadvantages of Risk-Reducing Surgery

ADVANTAGES

- Affords the best chance for a high-risk woman to avoid ovarian cancer, a serious and sometimes fatal disease
- Alleviates anxiety for a woman and her loved ones
- Often can be done through small incisions, reducing recovery time and the risk of complications
- Ends a woman's monthly menstrual cycle, which some women view as a benefit

DISADVANTAGES

- Does not reduce a woman's cancer risk to absolute zero
- Brings on sudden menopause, and the effects of that are not fully understood
- Requires time out from one's normal schedule, both for the surgery itself and recovery
- Involves short- and longer-term side effects

[Sidebar:]

My Experience

"For me, having my ovaries out was such a relief. I had breast cancer when I was 29 and had already been through chemotherapy. So, the only emotion I experienced was relief to have this over with and not worry about the possibility of my ovaries becoming cancerous. I really did get an emotional lift. I felt good that I had done everything I could to control my fate.

At the same time, I must say that intellectually, I do know there is still a small chance of cancer. My mother's ovarian cancer started in the pelvic lining, the peritoneum. I am vigilant about getting checkups – I have a CA-125 test, pelvic exam, and Pap smears, along with follow-up for my breast cancer – and leading a healthy lifestyle. Still, the relief feels like one-hundred-percent relief, even though intellectually I know it's not." -Sarah

⌘

"Before I had risk-reducing surgery, I felt like my risk for ovarian cancer was a ten, on a scale of one to ten. Now I'd say I feel like maybe I'm a three. Even though the ovaries are gone, my doctor was very clear with me that there is still always a possibility of getting ovarian cancer, because of whatever tissue is left behind." -Dora

⌘

"I have to say I was thrilled not to have my period anymore, or have to worry about getting pregnant! Those were important side benefits for me." -Paula

⌘

"Even though I experienced terrible hot flashes after surgery, in some ways things were better. I no longer had the migraines that I typically got along with my periods, no backaches, no mood swings. I have enjoyed the freedom of not having that monthly period – that's been a great physical comfort. And I like the peace of mind of knowing I have done something that reduces my risk dramatically – that's the emotional comfort. I think it gave my loved ones some sense of control as well." -Kelly

Choose a Surgeon

You also need to choose the physician who will perform your surgery and provide your immediate follow-up care (six to eight weeks). Two kinds of specialists are qualified to perform risk-reducing surgery: gynecologists and gynecologic oncologists.

- A **gynecologist** is specially trained in matters related to women's health, the female reproductive tract, and, if he or she is also an obstetrician, pregnancy and childbirth.
- A **gynecologic oncologist** has completed the same training as a gynecologist, along with more in-depth training in the diagnosis, treatment, and management of gynecologic cancers, including ovarian cancer.

Working with a Gynecologic Oncologist

If you have had a formal risk assessment, you likely will have access to gynecologic oncologists who specialize in managing high-risk women and performing risk-reducing surgery. You also can seek one out on your own. One good resource for finding a gynecologic oncologist in your area is the Society of Gynecologic Oncologists, which can be reached by phone at 1-800-444-4441 or through its Web site at www.sgo.org (or access the consumer version at www.wcn.org).

Working with such a specialist can be an advantage. Some studies of risk-reducing surgery have documented cases in which apparently healthy women were found to have an early-stage ovarian cancer during the procedure. Although this is not a common finding, many experts believe that it justifies working with a gynecologic oncologist. This surgeon has the training required to recognize the cancer, determine whether or not it has spread beyond the ovary (a process called staging), and if it has, remove all of it (a process known as optimal debulking). Accurate staging and optimal debulking are proven to increase the likelihood of a long-term remission, which means that there is no evidence of disease.

After surgery, your ovaries will need to be examined closely by a pathologist, a physician who evaluates the tissue for any evidence of disease. He or she should be informed that your ovaries were removed because you are at increased risk for ovarian cancer. Gynecologic oncologists at a cancer center or a hospital with a specialty cancer program are more likely to have access to pathologists with special expertise in evaluating gynecologic cancers.

Working with a Gynecologist

Even though there are many advantages to working with a gynecologic oncologist, you may prefer to work with a gynecologist. If you have established a good long-term relationship with your gynecologist, as many women have done through annual visits, you may feel more comfortable with having him or her do the surgery and providing your follow-up care.

As already mentioned, there have been some cases in which women were found to have ovarian cancer during risk-reducing surgery. You should discuss this possibility with your gynecologist before the procedure. If by some chance cancer is found, you will want a gynecologic oncologist to continue with the surgery. Such a specialist has much more experience operating on women with ovarian cancer and making sure that all of the cancer is removed. Your gynecologist may be able to have a gynecologic oncologist on call to step in if needed, or he or she may simply stop the surgery and reschedule it with a gynecologic oncologist at a later date.

Be sure to work out a contingency plan that is satisfactory to you. Also, make sure that your gynecologist has access to a pathologist (a physician who specializes in examining tissues to make a diagnosis) who is experienced in evaluating gynecologic cancers.

Experience Matters

Whichever type of surgeon you choose, you need to make sure that he or she is experienced with performing risk-reducing surgery and at managing women's care after the surgery. Do not be afraid to ask specific questions about the physician's level of experience in these areas. You want to work with someone who is already well-versed in the special health issues you face as someone who is considered "high-risk." You may decide to work with more than one physician — a gynecologic oncologist and a gynecologist, perhaps — and facilitate the communication between them. The questions at the end of this section should help get the information you need.

Make sure that your surgeon is experienced with performing risk-reducing surgery in high-risk women and managing their long-term care after the surgery. To cover both bases, you may need to work with more than one physician.

Make a Long-Term Care Plan

The physician who performs your surgery will monitor your condition over the short-term, typically six to eight weeks, to make sure that there are no unusual complications. However, you also will need to have long-term follow-up care — not only because of the remaining risk of cancer, but also because of surgery's potential side effects, such as surgical menopause. (See the later section titled "Long-Term Considerations" for a discussion of what this care will involve.) As you consider physicians who might perform the surgery, it's important that you raise this issue. After risk-reducing surgery, some women have reported feeling unsure about where to turn for help with questions or problems.

Keep in mind that any long-term care plan should include screening for breast cancer and other gynecologic cancers, such as cancer of the uterus, the endometrium (tissue that lines the uterus), or the cervix (the lower neck of the uterus, above the vagina). Removal of the ovaries and fallopian tubes does not protect you against these other gynecologic cancers. However, women are protected if they have a hysterectomy (removal of the uterus and/or cervix) as part of their risk-reducing surgery. The possibility of having more extensive surgery will be discussed in the next section, "What Surgery Involves."

[Sidebar:

My Experience

"I took about seven months to make the decision to have risk-reducing surgery. It wasn't something that was just presented to me, and then a month later I had it. Once I had the information, I checked it out with each of my doctors — gynecologist, primary care physician, rheumatologist — over the course of a year. I also spent four or five months reading about it. I really took my time." -Sarah

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"I wish I had thought more about who would manage my care after surgery and be able to tell me what I should and shouldn't do. I felt like I was alone in dealing with all of the physical side effects that started to happen. There really is no one medical specialist who has a full picture of what removing estrogen can do to a woman's body, and what to do about it. Women who are making the decision to have surgery really need to know this and plan ahead for it." -Lisa

§

"I am being managed by my gynecologist now. From the beginning, I kept him involved and informed. I had to explain what the HNPCC syndrome was, what it meant, what the risks were. I provided him with articles and pamphlets. I did that with my family doctor and my gastroenterologist as well. I felt comfortable with this. I like the sense of control that comes from being proactive." -Kelly

Verify Health Insurance Coverage

Women generally have not had trouble getting their health insurance plans to pay for risk-reducing surgery. However, many plans do require precertification for major medical procedures, so you should investigate whether this is true for your plan — and follow its directions accordingly.

You may be concerned about letting your health insurance company know that you have a higher-than-average risk of developing ovarian cancer. (Of course, if the plan has already paid for your genetic testing, it knows that you are concerned about your risk.) Some women express fears that their health insurance plans will try to drop them, or raise their premiums, once they have this information. If this concerns you, ask your doctor to indicate that a strong family history, rather than a positive genetic test result, is the reason for ordering the surgery. The results of your genetic test can be kept confidential.

Fortunately, genetic discrimination by insurance companies generally has not become the problem that the medical community had anticipated it would. New federal laws are helping. For example, the Health Insurance Portability and Accountability Act protects individuals in group health insurance plans from having genetic information considered as a preexisting condition and being used as justification for rate increases. The Genetic Information Nondiscrimination Act is currently under consideration by the U.S. Congress. This Act would prohibit health insurance companies from refusing to enroll individuals because of their or their family members' request for or receipt of genetic services. It would also prohibit insurers from raising group premiums based on this information.

In short, the law is on your side, and you should challenge your health insurance plan if you encounter any difficulties related to genetic testing or risk-reducing surgery.

For More Information

National Society of Genetic Counselors

(610) 872-7608

www.nsgc.org/consumer/index.asp

Visit the consumer area of the Web site for a brochure about genetic discrimination and related resources.

QUESTIONS TO ASK . . . While Choosing a Surgeon

These questions may be useful in your conversations with surgeons:

1. How often do you perform risk-reducing surgery in women who are considered high-risk for ovarian cancer, either because of a genetic mutation or a strong family history of the disease?
2. Do you ever recommend that women also have a hysterectomy (removal of the uterus and/or cervix) as part of the procedure? If so, in what cases?
3. How much experience have you had managing the health of high-risk women? In your view, what are the most pressing issues they confront after surgery?

4. If you have not had much experience in this area, can you refer me to someone who has?
5. How would we work together to manage my follow-up care? Would you manage all aspects of that care, or would you prefer that I see another physician as well? How would the two of you communicate?
6. What do you recommend for dealing with the effects of surgical menopause?
7. How often would you want to see me after surgery?
8. What should I do if I have problems or questions in between visits? Who in your practice will be able to field my questions?

What Surgery Involves

Once you choose a surgeon, you will need to work with him or her to decide what type of surgery you are going to have. You also will need to schedule your pre-surgical testing and make any arrangements you need for assistance or time off during your recovery.

Types of Procedures

In many cases, risk-reducing surgery can be done laparoscopically, with the ovaries and fallopian tubes being removed through small incisions in the pelvic region. This is still considered major surgery. However, as compared with a larger abdominal incision, the laparoscopic approach lowers the risk of complications from the surgery itself, shortens recovery time, and causes less scarring. There are some cases in which the physician recommends more extensive surgery that includes removal of the uterus and cervix, a procedure called hysterectomy. Some women also choose to have the more extensive surgery as well, usually because of health-related concerns.

[Suggested visuals: simple diagrams of the various procedures.]

Women who undergo risk-reducing surgery have one of the following procedures:

- **Laparoscopic Bilateral Salpingo-oophorectomy (BSO)**

The surgeon makes several small incisions in the abdominal wall, and then uses a special device called a laparoscope to perform the procedure. First, a tube is inserted through the laparoscope to inflate the pelvis with carbon dioxide gas. Then the surgeon inserts a lighted fiber optic camera that allows for viewing of the internal organs on a television monitor. He or she uses specialized surgical instruments to remove the ovaries and fallopian tubes through the small incisions. If these organs and the surrounding tissue appear healthy, there is no need for the surgeon to go any further. He or she would send the tissue to a pathologist for close examination under a microscope, just to be certain that no early-stage cancer is present.

Laparoscopic BSO typically lasts about one to one-and-a-half hours.

- **Abdominal BSO**

There are some cases in which the surgeon needs to make a larger incision to perform BSO. If a woman has scar tissue (technically known as adhesions) from previous abdominal or pelvic surgeries, for example, it may be impossible to access the ovaries and fallopian tubes laparoscopically. The surgeon would need to make a bikini incision – a horizontal incision just below the navel – to complete the surgery.

The surgeon also might need to make a longer vertical incision down the abdomen if he or she sees something suspicious that may be suggestive of cancer. He or she would want to inspect the area thoroughly and send any suspicious tissue for immediate examination by a pathologist, a process better known as “frozen section.” If the surgeon’s suspicions are not confirmed, no further surgery would be needed.

Abdominal BSO generally lasts about two hours, perhaps a bit longer if the surgeon needs to do some further exploration.

- **BSO with Laparoscopically Assisted Vaginal Hysterectomy (LVAH)**

The surgeon removes the ovaries and fallopian tubes laparoscopically, as already described, and begins the process of detaching the uterus and cervix. The hysterectomy is completed through an incision in the vagina. This approach allows women to avoid the longer abdominal incision that was traditionally needed to perform a hysterectomy.

BSO with LAVH typically lasts about two to two-and-a-half hours.

- **Total Abdominal Hysterectomy/Bilateral Salpingo-oophorectomy (TAH/BSO)**

To perform TAH/BSO, the surgeon makes a four- to six-inch vertical incision down the abdomen and removes the ovaries, fallopian tubes, uterus, and cervix. The surgeon would want to inspect the area thoroughly.

TAH/BSO typically lasts about three to four hours.

Why You Might Want, or Need, a Hysterectomy

There are a number of cases in which removal of the uterus and cervix (the neck of the uterus, which connects it with the vagina) may be warranted. You will need to talk to your physician about each of these possibilities in advance and consider whether or not it makes sense to have the more extensive surgery.

Possible reasons for having a full hysterectomy in addition to BSO include:

- **You have an HNPCC mutation.**

If you have tested positive for the genetic mutation that is linked with Hereditary Non-Polyposis Colorectal Cancer (HNPCC), you are considered to be at higher-than-average risk not only for ovarian cancer, but for cancer of the uterus as well.

- **You are concerned about a possible increased endometrial cancer risk linked to the BRCA mutation.**
The endometrium is the inner lining of the uterus. Some preliminary research has suggested that women with a BRCA mutation may also be at increased risk for a certain type of endometrial cancer (called papillary serous carcinoma of the endometrium) that is closely related to ovarian cancer.
- **You are concerned about increased uterine cancer risk associated with taking tamoxifen.**
Many women who are considered high-risk for ovarian cancer also take the drug tamoxifen to reduce breast cancer risk. While tamoxifen blocks the effect of the hormone estrogen on breast tissue, it actually amplifies its effect on uterine tissue, leading to an increased risk of uterine cancer.
- **You have a history of problems involving the uterus.**
Hysterectomy may be indicated for problems such as abnormal uterine bleeding, uterine fibroids (noncancerous growths that sometimes cause pain and/or heavy bleeding), or endometriosis (a condition in which tissue from the uterine lining grows outside the uterus).
- **You are considering hormone replacement therapy (HRT).**
Women choosing HRT after hysterectomy need only take estrogen. Women choosing HRT who keep the uterus require the combination of estrogen *and* progesterone. This combination therapy may be linked to increased risk of heart disease, stroke, blood clots, and breast cancer. For a more detailed discussion of HRT, see the later section "After Surgery: Managing Physical Consequences."
- **You have a strong preference for the more complete surgery.**
Some women simply have a strong personal preference for undergoing hysterectomy along with the BSO. They reason that, if they are going to have surgery to have some of their reproductive organs removed, they might as well have all of them removed to guard against other future problems. Also, some surgeons feel that the only way to be sure that all fallopian tube tissue has been removed is to remove the uterus.
- **You are approaching the age of menopause.**
If you are nearing natural menopause or already in menopause, you may have gotten used to the fact that your reproductive years are ending, and this may make the idea of a hysterectomy more acceptable to you.
- **Ovarian cancer is found during the surgery.**
Although this is rare, it can happen. There have been documented cases in which physicians have found ovarian cancer — typically early-stage cancer — while performing risk-reducing BSO in an apparently healthy woman with no signs or symptoms of ovarian cancer.

Why You Might Not Want a Hysterectomy

The decision not to have a hysterectomy as part of your risk-reducing surgery may be based on the following reasons:

- **Your uterus and cervix are healthy and not implicated in any future risk of disease.**
Research done to date has not established a definite connection between the risk of ovarian cancer and the risk of other gynecologic problems. Therefore, you may not see the sense in having these organs removed.
- **You want to avoid more invasive surgery and the potential side effects of hysterectomy.**

Laparoscopic BSO is a major procedure, but the smaller incisions generally mean a faster recovery time, lower risk of complications, and less disruption in your life. BSO also eliminates the risk of additional side effects from a hysterectomy.

- **You have a strong personal preference to keep your uterus and cervix.**
Often this decision comes down to strong personal preference. For many women, surgery to remove the reproductive organs is an emotional experience as much as it is a physical one. And some simply prefer to have the least amount of surgery possible.

[Sidebar:

My Experience

"The hardest decision was whether to have just the ovaries and fallopian tubes removed or have a full hysterectomy. The doctors wanted to remove everything, but I couldn't decide whether or not there was a real benefit to that. Did I really need it? When I talked to more experts, I found that no one really went either way and said, 'Yes, you should have this,' or 'No, you shouldn't have it.' Ultimately I decided just to have the ovaries and fallopian tubes removed, because that was where the risk of problems was." -Dina

§

"I decided to have a total abdominal hysterectomy. What helped me make up my mind was, about a month before the surgery, my gynecologist tried to do a uterine biopsy (removal of cells from the uterus for examination). Because I have stenosis (narrowing) of the cervix, she wasn't able to do the test. That was what made me go from just having the ovaries out to having everything removed. She said it wouldn't be easy to check my uterus, and that just sort of pushed me over the edge to having everything taken out and not needing to worry about it again." -Sarah

§

"I had a laparoscopically assisted vaginal hysterectomy. Actually I had the ovaries, fallopian tubes, and uterus above the cervix. I have my cervix, but everything above it is gone. The reason I chose to do that, besides just having the ovaries removed as I had originally planned, was that my gynecologist noted that taking tamoxifen increased my risk of uterine cancer. She said, 'Once you don't have your ovaries, you really don't need the uterus. We might as well take both.' And I thought there was some sense in that, so that's what I did." -Theresa

Practical Planning Before Surgery

Even though you are not sick, you are about to have major surgery. Whether you have laparoscopic surgery or a larger incision, you will need to give yourself time to recover and rely on the assistance of others. It is a good idea to prepare for this in advance. Some practical steps you can take include the following:

- **Determine who is going to accompany you to your surgery, talk with the doctor after it's over, and generally act as your advocate.** It's essential to have a trusted family member or friend act as your advocate while you can't do so yourself. The nurses and other medical staff members who will care for you after surgery will be responsible for many other patients, too. So it's always wise to have someone with you who can ask questions and get their attention.
- **Prepare a space at home for your recovery.** Make sure you're well stocked with books, magazines, a television, a radio — anything you feel you might need. Keep in mind that it may be difficult for you to climb steps and lift things during the first several days after your surgery.
- **As much as possible, delegate some of the tasks that you are used to handling at home and at work.** Whether at work or at home, plan for who will take over your responsibilities. For

laparoscopic surgery, it may be three or three weeks before you have all your energy back, and for abdominal surgery, about four to six weeks.

- If you live alone, try to have someone come stay with you after your surgery. This is especially critical if you are going to have major abdominal surgery, as opposed to laparoscopic surgery. See if you can get a relative or close friend to stay with you for at least part of that time.

Even though you are not sick, you are about to have major surgery. Whether you have laparoscopic surgery or a larger incision, you will need to give yourself time to recover and rely on the assistance of others.

[Sidebar:]

My Experience

"I had my ex-husband keep our two kids for the first couple of days while I was recovering. I did talk to my children a little bit about the fact that I was having an operation, but I made sure they knew I was OK.

My dad stayed with me for the first couple of weeks until I was able to be up and driving again. He took care of me and made sure I had meals to eat. He also left my freezer stocked before he left, which really helped.

I also was very thankful that my gynecologist, knowing that I was going to have extensive surgery, signed me out of work for eight weeks. She knew that, once I went back to work, I wasn't going to get any rest, since I am a single parent. She said, 'You need as much time at home to recover before you have to go back into full swing.' I thought she was very wise in that." -Theresa

§

"My sister came with me for the surgery and stayed a few days. My oldest daughter also came up from college, about an hour away, for a couple of days to help me. Then my friends were also there, in case I needed them." -Dora

§

"Go out and find a pair of pants with a waistband that doesn't rub, like sweatpants. I am perfectly serious. That was one of the biggest challenges I faced after surgery." -Penny

The Partner's Experience

"I offered to take care of everything for a while — the kids, the house, meals. I told her to focus on getting better. I think it lifted a real burden from her to know that. I tried to give her a shoulder to cry on when she needed it, and to reassure her that I was there for her and would still love her when this was all over." -Joe

§

"I tried to give emotional support but also help with all of the mundane, day-to-day stuff. I was also kind of surprised at how long it took her to recover from the surgery. It certainly was no minor deal." -Mark

Pre-surgical Procedures and Testing

All medical centers have set procedures for surgical patients to follow. Generally, you can expect to meet with an anesthesiologist in advance of your surgery and have some standard pre-surgical tests. These may include:

- Complete blood count
- Coagulation studies

- Chest x-ray
- Electrocardiogram, or EKG, a test that records the electrical activity of the heart
- Pregnancy test, if you are pre-menopausal.

Your physician also should perform a CA-125 test and a transvaginal ultrasound. In some cases, he or she may need to order another imaging test, such as a CT scan. These are done to make sure that the ovaries are healthy.

You also will go through an informed consent process at some point before your surgery. Your physician should explain the surgery and its risks and give you a written form that explains them, which you will then be asked to sign. He or she also will give you instructions for the day of your surgery, or arrange for a staff member to contact you with that information.

You should also tell your physician about any medications you are taking, including aspirin and aspirin-containing drugs, nonsteroidal anti-inflammatory drugs (NSAIDs, such as ibuprofen), blood thinners, and any vitamin or herbal supplements. Some of these medicines can cause bleeding and may need to be stopped before surgery.

Recovering from Surgery: What to Expect

The length of your hospital stay depends on the type of procedure you have, as shown in the following table:

Type of Procedure	Length of Stay
Laparoscopic BSO	One night, or released same day
BSO with LVAH	One night
Abdominal surgery (BSO or TAH/BSO)	2-3 days

During your stay, nurses will monitor you for any signs of infection, such as a fever or unusual redness and leaking from your incision. You may be given a patient-controlled analgesic (PCA) pump that allows you to administer pain medication as you need it. As you recover, you also will take some oral pain medications, now and for a few weeks after your surgery.

The same day or the very next day, you'll be expected to get up and walk around. This may be painful at first but it's important to your recovery. At first, you may not be allowed to take any food or drink by mouth. After that, you'll probably be restricted to a diet of fluids until your doctor is sure that your intestines are functioning normally. The gastrointestinal system is the last part of the body to recover from the effects of general anesthesia.

Side Effects

In the days and weeks after surgery, you could experience any or all of the following side effects.

- **Pain:** If you had laparoscopic surgery, your pelvis and abdomen were inflated with carbon dioxide, and this can cause some residual pain. You also may experience some pain at the site of the incision(s). Your physician likely will prescribe pain medication to be taken during the first week or two after surgery.
- **Fatigue:** Fatigue is common after the surgery. You may find that you feel tired sooner and you require more rest. Generally, it takes three to four weeks after laparoscopic surgery to resume your usual activity level, and up to six weeks for surgery that involves the longer abdominal incision.
- **Changes in your digestive system:** You may find that you have less of an appetite than normal in the days after surgery. Some women find it helpful to eat more frequent, smaller meals instead of

three large meals. You also may have less frequent bowel movements until your gastrointestinal system gets back to normal. Your physician may recommend that you take a stool softener.

- **Surgical menopause:** Within days or even hours of surgery, you may begin to experience side effects related to the loss of estrogen. These effects are likely to be more pronounced if you had not yet started the process of natural menopause. They can include intense hot flashes, fatigue, mood swings, and vaginal dryness and irritation. Because these side effects will require ongoing management over the long-term, we will discuss them in the next section, "After Surgery: Managing Side Effects."

Limits on Physical Activity

The following are typical recommendations for resuming normal activities. Be sure to check with your physician for specific instructions:

Activity	Time before resuming
Driving a car	2 weeks
Heavy lifting	2 weeks
Exercise	6 weeks

[Sidebar:]

My Experience

"When I was in the hospital, I did not do very much. When I got home, although I was still weak, I tried to do the stairs at least once a day, take a short walk to the mailbox. I also had someone take me somewhere every day, just so I would get out of the house. Soon enough, I was able to get back to my regular routine." -Dina

"It was not an easy surgery, but I had adhesions from my previous abdominal surgery, so I think that made it more difficult for me. And after the surgery, my colon decided it just wasn't going to work. So I had to spend some additional time in the hospital. After that, it took about three weeks for me to feel really well, and I was back at work in six weeks. I arranged for that time off in advance.

My advice after surgery would be to walk, walk, walk. It is amazing what that will do for you. It helps with a lot of things. It helps you feel like eating and sleeping, it helps you gain strength, and emotionally it just helps to get outside and feel better. You don't have to run a marathon. Just do what you can, day by day." -Kelly

"I didn't find that I really needed emotional support after surgery. I had an awful lot of help from my husband and a few close friends, who would have been there for me emotionally if I had needed it. But just physically they helped me out a lot. I had friends dropping by casseroles for dinner and my husband was doing everything around the house. So that made it very easy for me to focus on my recovery." -Sarah

"What helped me the most was just taking time off after surgery and having absolutely no obligations whatsoever. It doesn't ever happen in my life, so just allowing myself that time was nice. Allowing myself to just read or relax with a cup of tea, just giving myself the chance to recover, made a big difference." -Dora

"As far as recovery goes, the biggest thing for me was just listening to my body. When it said, 'Go lay down,' I would listen to it and do that." -Theresa

When to Call Your Physician

You should call your physician if you experience any of the following symptoms:

- A temperature over 100.4 degrees. For at least a couple of weeks, you should take your temperature in the morning and evening.
- Increase in swelling or redness at your incision(s)
- Any drainage from your incision
- Pain not relieved by your pain medicine
- Vaginal discharge with itching or a bad-smelling odor
- Nausea, vomiting, or stomach pain
- Any difficulty with urinating, such as pain, burning, urinating often, or being unable to reach the bathroom on time.

Follow-up Visits with Your Physician

The physician who performed your surgery should see you for an office visit about two weeks and again at about four weeks after surgery. He or she will want to check to make sure your incision(s) is healing properly. If you had a hysterectomy as part of your risk-reducing surgery, you can expect to have a pelvic exam at about four weeks.

Regardless of who is going to provide your long-term care (your surgeon or another physician), make sure you have some strategy in place to get the help you need in coping with side effects. This might mean making an appointment specifically to discuss potential problems and solutions, and then scheduling more frequent office visits during the first year after surgery. At the very least, be sure you know how to contact your doctor when you have a problem or question.

After Surgery: Managing the Physical and Emotional Impact

Just as individuals can experience different effects when taking the same medication, you have no way of knowing exactly how risk-reducing surgery will affect you. Women tend to fall along a broad spectrum: at one end are those who experience few or no effects, while at the other are those who experience many effects that impact their quality of life. Most fall somewhere in between. Researchers are now working to build a more complete understanding of how removing the ovaries impacts a woman's health and well-being.

If you are pre-menopausal, you are likely to experience effects of early menopause due to surgery, or "surgical menopause." The most common are hot flashes, night sweats, and vaginal dryness. Others include headaches, fatigue, and sleep problems. Some women report having mood changes, such as anxiety and depression, and changes in thinking, such as forgetfulness and loss of mental sharpness. Still others have reported effects such as weight gain, change in body shape, and joint pain. Also, women who have the surgery are at greater risk of osteoporosis, or thinning of the bones, and possibly of heart disease as well. (Women also can experience sexual side effects and a lessened libido, or sex drive, which will be discussed in Section 5.)

If you already experiencing natural menopause, you may find that your menopausal symptoms do not change, or you may find that they intensify or that you experience some new symptoms.

There are some strategies you can use to manage these effects. Hormone replacement therapy (HRT) is one option, but some studies have raised questions about its potential health risks. More research on HRT is needed, both for women in general and for those who are considered to be at higher-than-average risk of breast and ovarian cancer. Other options include non-hormonal medications, natural

remedies, and lifestyle changes such as diet and exercise. The effectiveness of these and other strategies is under investigation, so you likely will need to work with your health care team to tailor a solution that works for you.

In spite of the physical effects of risk-reducing surgery, however, many women report one very positive effect: the relief that comes from significantly reducing their risk of ovarian cancer.

Just as individuals can experience different effects when taking the same medication, you have no way of knowing precisely how the removal of your ovaries will affect you. Women can fall anywhere along a broad spectrum: at one end are those who experience a few or no effects, while at the other are those who experience many effects that impact their quality of life. Most fall somewhere in between.

[Sidebar:]

My Experience

"No one ever said to me, 'You may feel a lot better emotionally when this is done.' What they tended to focus on was how I could feel worse emotionally. No one said that I might feel like a weight had been lifted from my shoulders. I think women need to know that.

I am very happy with my decision. It was the best thing I ever did." -Kelly

"My health care team covered most of the symptoms I might experience after surgery. I think what was lacking was a full explanation of the big difference between surgical menopause and natural menopause. I really thought that surgical menopause would be more gradual, but it is much more pronounced and they didn't tell me that.

At the same time, surgery was not as scary or horrible as I thought it might be. I had never had surgery before and I was pretty frightened about it, but my recovery was good. I felt great afterwards. It took such a weight off my mind. I have many of the symptoms I read about, but they don't really interfere with my life. And surgery has brought such a sense of relief that any of the symptoms are still worth it." -Paula

"I wish my health care team had talked more about the potential after-effects of being thrown into menopause. Everybody knows you are going to have night sweats and hot flashes, but there are other things that can happen afterwards that aren't expected. I never would have guessed that I would have insomnia and joint pain. Also, I always had 20/20 vision, and within a year after surgery, my vision started to go downhill rapidly. I spoke with some doctors and they said that this can be a side effect. I guess a more detailed discussion before surgery of what *could* happen would have made me feel better prepared." -Agnes

"There was little talk of possible side effects or drawbacks of the surgery. I knew about hot flashes and all of the common effects that could happen. We talked about different ways of dealing with them. So I felt pretty much like, 'Oh, those common things that happen to women in menopause will be no problem, because there are ways to combat them.' But it's really been much so much worse than I ever imagined." -Lisa

The Partner's Experience

"My partner was already having menopausal symptoms, so we had already gone through a lot of the issues related to menopause. So the surgery really didn't present us with any additional challenges. Overall, the quality of life is basically the same as before, so I think it was a good decision and the right decision.

The greatest benefit is that she is not obsessing about this anymore. It's just one less thing she has to worry about. At the time she was contemplating surgery, she had several family members who were dying of cancer. Her doctor told her, 'I can protect you pretty well from breast cancer, but I cannot protect you from ovarian.' I'd rather have my partner with me for a lifetime than take the risk of not having her." -Connie

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"My wife was not even close to menopause when she had the surgery. So we found ourselves there all at once, almost overnight. For her it was very intense and physically uncomfortable, and she was very unhappy. We hadn't really expected this and probably would benefited from knowing more about what *could* happen. The surgery was presented to us as something we had to do, given her risk, and the quality-of-life piece never really made it to the table. That might be because the effects weren't really understood when we made our decision, which was a few years ago now.

Despite that, I know my wife went to her doctor the other day and met a woman her age who also had the surgery and was found to have ovarian cancer, and now she is going through chemo. So I guess you could say there's diminished quality of life, on the one hand, and then there's being alive, on the other." -Mark

§

"My wife was certainly pre-menopausal and the reactions to surgery were extreme for a long time. It was almost a year before the physical side of it became less complicated. The emotional side still exists today and it's almost five years later.

I would advise a pre-menopausal woman to carefully consider and talk about the changes that could occur once surgery is completed. I think it's easy for a positive genetic test result to override any rational conversation about what the consequences of surgery could be. My wife's immediate reaction was, 'Well, I am not having any more children, I don't need that body part,' and she was ready to have surgery right then and there. Given the side effects she has had, my wife might have waited a little bit longer to have surgery, until she was closer to menopause, but I think ultimately she would have gone through with it. Of course, because there is no accurate early diagnosis test for ovarian cancer, waiting to have surgery does mean that you are taking the risk that the cancer will sneak up on you." -Timothy

Loss of Estrogen

Removing the ovaries removes the body's source of estrogen and progesterone. Hormone replacement therapy (HRT) was once viewed as an excellent solution for women who wanted to relieve menopausal symptoms due to estrogen loss and reduce their risk of heart disease and osteoporosis. In the past, it was routinely prescribed to women who underwent risk-reducing surgery before menopause. HRT involves using a pill, patch, or implant that contains the hormone estrogen alone or a combination of estrogen and progestin (a synthetic form of the hormone progesterone) to replace the hormones that are no longer present in the body naturally.

Over the last few years, however, a number of studies have suggested that HRT has some risks that women should consider when deciding whether or not to take it.

Recent Research Findings

In 2002, the Women's Health Initiative, a large-scale clinical trial by the National Institutes of Health, suggested that the risks of HRT may outweigh the benefits. More than 16,000 post-menopausal women participating in the study were randomly assigned to take either estrogen-progestin HRT or a placebo (inactive pill). After about five years of follow-up, the HRT group had 26 percent more cases of breast cancer, a 29 percent increase in heart attack rate, a 41 percent increase in the rate of stroke, and

double the rate of leg and pulmonary blood clots. They had fewer cases of hip fractures and colon cancer. The trial was stopped early as a result.⁶

Other studies have raised specific concerns about HRT in relation to the risk of cancer. A British study of more than one million women found that those who took HRT were more likely to develop and die from breast cancer. Women who were using combination HRT at the time of enrollment were twice as likely to develop breast cancer, while women taking estrogen only were 30 percent more likely to develop it.⁷

Interpreting the Findings

While these percentages are significant, it is very important to keep the actual numbers in perspective. In the Women's Health Initiative study, for example, 38 out of 10,000 women taking HRT developed breast cancer annually, versus 30 out of 10,000 in the no-HRT group. These eight additional breast cancer cases account for the 26 percent increase in risk reported by the study.

According to the American College of Obstetricians and Gynecologists, which in fall 2004 published its *Task Force Report on Hormone Therapy*, these study results do not mean that taking HRT should be off-limits for all women. Rather, these results suggest that all women need to consider the potential risks of HRT before taking it to relieve menopausal symptoms. In addition, the report stresses that:

- Women should not take HRT to prevent cardiovascular disease, given the results of the Women's Health Initiative study.
- The average age of women in the study was 63 – about ten years older than the typical woman seeking relief at the onset of natural menopause. This is also considerably older than women are when they are making decisions about risk-reducing surgery.

All women need to make the decision about whether or not to use HRT in close consultation with their physicians, carefully weighing the potential benefits and risks.

There is particular concern about the use of HRT by women who are considered high-risk for ovarian and/or breast cancer, whether due to a BRCA1 or BRCA2 mutation, a strong family history of disease, or both. This concern is relevant to women who undergo risk-reducing surgery for ovarian cancer. Physicians' recommendations tend to vary:

- Some physicians definitely would not recommend HRT for these women, particularly in light of the possible increased risk of breast cancer.
- Others feel that it is acceptable when used only for the short term –for a few years at most, and certainly no more than five years – and in the lowest dose needed to provide relief from the symptoms of surgical menopause.
- Still others feel that low-dose HRT is acceptable until age 50, the time at which a woman is likely to go through natural menopause.

Considering HRT as an Option

Given these concerns, it is most important to discuss these issues in advance of your surgery. If you are very concerned about the effects of surgical menopause, you may plan to start HRT right after surgery,

⁶ Rossouw JE, Anderson GL, Prentice RL, et. al. "Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results From the Women's Health Initiative randomized controlled trial." *Journal of the American Medical Association* 2002 Jul 17; 288(3):321-33.

⁷ Beral V, Million Women Study Collaborators. "Breast cancer and hormone-replacement therapy in the Million Women Study." *Lancet* 2003 Aug 9; 362(9382):419-27.

and then gradually wean off it as your body adjusts to the significant drop in natural estrogen levels. On the other hand, you may want to wait and see how your body reacts to the surgery, perhaps trying alternate strategies for relief from menopausal symptoms. Or, you may decide to forgo HRT entirely, no matter how you feel after surgery, because of its potential risks.

The key is to work with your health care team to find the best possible plan for you.

There is particular concern about the use of hormone replacement therapy in women who are considered high-risk for ovarian and/or breast cancer, whether due to a BRCA1 or BRCA2 mutation, a strong family history of disease, or both. However, for some women, the impact of surgical menopause on quality of life may justify short-term use of HRT at the lowest dose needed to offer relief.

[Sidebar:

My Experience

"I wish I had known that physicians do not yet really have a clear understanding of the role of estrogen in the body. I have yet to find a physician who really understands, at least in my body, what estrogen is responsible for. I wish I had known the limits of modern medicine. I wish I had known that when you basically go cold turkey to having no estrogen in the body, you might suffer repercussions.

I have had a wide range of side effects. About six months after the surgery, my joints started swelling — all of my major joints, shoulders and knees and hips — and I still have this. The hot flashes weren't as upsetting to me as the fact that I was hobbling around like a person twice my age. I also had chronic urinary tract infections and kidney infections. I have had hair fall out. My body shape has changed — I gain weight without eating. I forget things easily; I seem to have lost a lot of memories formed before my surgery. I often struggle to find the right word. My stamina is very low. My allergies are worse. None of these things were anything I had expected to happen." -Lisa

"My gynecologist went over the possible side effects of surgery with me, such as the fact that my hot flashes would certainly continue or possibly worsen, I'd have vaginal dryness, etc. I was already familiar with these symptoms because I had been perimenopausal for about five years, but I was still worried about how bad they could get. Actually, the effects after surgery were not as bad as I had expected, and that was such a relief. If I had known that would be the case, I wouldn't have worried as much.

Of course, I have since found out that this is not true of all women. Other people have had much worse times after surgery than I had." -Sarah

Hot Flashes

Hot flashes are a common symptom of surgical menopause. A hot flash is a sudden onset of warmth that may begin in the chest and move to the face and neck, sometimes accompanied by profuse sweating, red blotching of the skin, anxiety, and/or heart palpitations. They occur because the lack of estrogen causes a hormone imbalance, which in turn affects the brain's temperature-regulating center. Hot flashes can affect your ability to concentrate, work, and sleep. They may occur rarely or many times a day.

Many hot flashes require no treatment, but for those that do, there are a number of options that have been helpful for some women. They are listed below in no particular order. If you wish to avoid medications, you may be more likely to try behavioral changes first (see the boxed tips) or alternative treatments such as acupuncture or yoga.

- **Antidepressants:** Antidepressant medications such as Effexor® (venlafaxine), Paxil® (paroxetine), and Prozac® (fluoxetine), given in lower doses than those used to treat depression, can reduce the severity and frequency of hot flashes. Venlafaxine has been studied the most and shown proven benefit, but the other medications have been reported as beneficial. Like all medications, these have other side effects, such as nausea, that must be considered.
- **Other types of medication:** The anti-seizure medication Neurontin® (gabapentin) has been found to help with hot flashes. Anti-hypertensives, which are medications that reduce high blood pressure, also can be effective. Examples include Catapres® (clonidine) and Aldoril® (methyldopa). Megace® (megestrol acetate) is a form of progestin most commonly used to treat metastatic breast cancer. At low doses it offers some women relief from hot flashes.
- **Black cohosh:** A plant-based estrogen also known as snakeroot, "squaw" root, and bugbane, it has been used for centuries in the treatment of women's reproductive disorders. Some women claim to find relief by taking it, although more studies are needed to confirm its effectiveness. Also, it may act on the body's tissues in much the same way that estrogen does, and this is a concern for women who are considered high-risk for breast and ovarian cancer.
- **Vitamin E:** Some research suggests that Vitamin E can be helpful with hot flashes.
- **Acupuncture:** A practice derived from traditional Chinese medicine, acupuncture involves placing small needles at certain key points along the skin to provide relief from pain or irritation. Some women find it offers relief, although the results of studies have been mixed.
- **Estrogen-containing foods, such as soy protein and soy supplements:** Some women find that eating foods rich in soy, such as soymilk, tofu, and soybeans, helps to moderate hot flashes. However, soy is a form of plant-based estrogen, and it may affect the body in the same way that the hormone does.

You need to work with your health care team to determine the solution that is right for you. Some women also find that certain behavioral changes can help. See the boxed tips for details.

Tips for Hot Flash Relief

- Avoid spicy foods, hot drinks, and alcoholic beverages.
- Wear loosely woven cotton clothing during the day, and lightweight nightclothes for sleep. Avoid turtlenecks and heavy sweaters.
- Dress in layers that can be removed easily as needed.
- Keep your home and office at a comfortable temperature.
- Carry a water bottle and a hand-held fan.
- Learn and practice stress management techniques such as deep abdominal breathing, meditation, and/or yoga.

[Sidebar:]

My Experience

"When I went into surgery, I was in my early 40s and had not had any menopausal symptoms. I experienced intense hot flashes and night sweats, which I think are even worse than the ones that happen during the day. Because of my breast cancer history, my doctors did not recommend hormone replacement therapy, so I had some discussions with them about alternatives.

Some self-talk helps, too. When I have hot flashes, I tell myself, 'OK, I'm having them sooner and younger in my life, but that doesn't mean I would have escaped them if I hadn't had surgery.' Then I think more about it and say, 'Nobody ever died from a hot flash, whereas people die from ovarian cancer, so just live with it.' - Theresa

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"I wasn't prepared for was the intensity of my hot flashes and night sweats. I started having hot flashes within 24 hours after surgery. They got to the point where I couldn't even count how many I was having in a hour, and there were times I thought to myself, 'I just can't stand this.' The first summer after my surgery, the only way I could sleep was to have my central air on with two pedestal fans directed at me. Just getting through that was a challenge. I chose not to use hormone replacement therapy; I went on a drug called Effexor instead, which has helped make things more tolerable.

What's also helped is learning what my triggers are and avoiding them. It's very individual - what is going to trigger hot flashes for someone else may not trigger them for you. Things like the fact that red wine triggers a hot flash for me, but white wine doesn't. My other triggers include humid weather, walking into a house that is warm, being overtired or stressed, being in a crowded place like a movie theater. If my dogs lie too close for me that can trigger it. Another person being too close can trigger it. Sitting under a lamp to read or work can trigger it. Cooking over a stove can trigger it." -Kelly

Fatigue and Insomnia

Many women report that they experience intense fatigue as a symptom of surgical menopause. This may be due to the body's getting back to normal after surgery, or to having trouble sleeping (insomnia). Exercising regularly - even when you don't feel like it - is the best strategy for boosting your energy level. If you were not physically active before, start out with a less intense activity, such as walking, and work up to something more rigorous.

[Sidebar:]

My Experience

"In addition to having hot flashes, I had trouble sleeping regularly - even several months after surgery. What really helped was changing my diet and exercising more frequently. I love junk food. Not that I still don't eat it, but I have tried to shift toward three or four servings a day of healthier foods like fruit, vegetables, fish. Thanks to that and a regular exercise program, I can sleep fine and I don't wake up. I still have the hot flashes, but it really helped everything else." -Dina

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"My largest complaint is that, still to this day, I find that I have to take sleeping medication. Not as often as before, and not every night, but just the fact that I have to take it maybe two to three times a week, that bothers me." - Agnes

Urinary Incontinence/ Urinary Tract Infections

The decrease in estrogen levels can lead to urinary problems such as incontinence and urinary tract infections.

The muscles that control urinary flow may become weaker, and this can cause incontinence (the inability to control urinary flow). You may constantly feel like you need to urinate, a condition known as urge incontinence, or you may involuntarily release urine when you laugh or sneeze, a condition called stress incontinence. Doing Kegel exercises, which involve contracting the pelvic floor muscles for several seconds and then releasing them, can help over time. They need to be done at least a couple of times per day, and it may take as long as six to 12 weeks to notice any improvement. Avoiding or limiting food and drink that are potentially irritating, such as caffeine, acidic or spicy foods, alcohol, and artificial sweeteners, may also help. If needed, there are medications you can take to control symptoms. Discuss these options with your doctor.

As the tissues of the vagina and bladder become thinner and lose elasticity, the risk of urinary tract infections (UTI) increases. These bacterial infections can cause pain, a burning sensation, and a sense of urinary urgency. Many women find that drinking plenty of water and unsweetened cranberry juice can help prevent urinary tract infections. If you develop an infection, you will need to see your doctor for a course of antibiotics.

Joint Pain

A number of studies have suggested that estrogen has a protective effect on the cartilage that cushions the joints in your hands, knees, hips, and spine. This may explain why some women report that their joints ache after risk-reducing surgery. Over time, you may be at increased risk of developing osteoarthritis, a condition that occurs when your cartilage breaks down more quickly than your body can replace it.

Pain relievers such as aspirin, acetaminophen, and ibuprofen are usually helpful. Over-the-counter rubs and heating pads also may offer some relief. Some studies have suggested that taking supplements of glucosamine or chondroitin, two of the many components of cartilage, also may be helpful. Exercising and maintaining a healthy weight also can help keep the condition from worsening.

[Sidebar:]

My Experience

"One side effect I didn't dream of having was joint pain, which started probably eight months out from surgery and ended I guess about a year later. It was mostly in my fingers and my elbows, with some additional minor pain in my knee. I found that exercising regularly helped a great deal." -Agnes

Difficulty with Concentration and Memory

Women often report memory and concentration changes around the time of menopause, but it is not clear if these changes are due to loss of estrogen. More research is needed to confirm this connection. Some research points to the importance of "exercising the brain" as we age — by doing mentally stimulating activities like knitting and crossword puzzles.

Body Image, Anxiety, and Other Emotional Effects

The side effects of risk-reducing surgery can be emotional as well as physical. Having the ovaries, fallopian tubes, and perhaps the uterus and cervix removed can make some women feel as if they have lost an important part of their female identity. This is especially true for women who are potentially

many years away from experiencing natural menopause. Some women find that they mourn this loss, even if they have finished having children.

Even though risk-reducing surgery can significantly improve cancer-related worry, some women experience anxiety in its aftermath. Symptoms of surgical menopause, such as hot flashes, can be sudden and intense, and they can make some women feel they have lost control over their own bodies. The loss of estrogen itself is thought to be responsible for the mood changes and anxiety that some women experience. Another source of emotional distress can be the impact of surgery on intimate relationships, due to the sexual side effects and/or lessening in sex drive it can cause (see Section 5 for a more complete discussion.)

Another source of anxiety for some women is the knowledge that, even though they have reduced their ovarian cancer risk significantly, there is still a small chance of developing primary peritoneal carcinoma. Doctors' appointments and exams can be especially anxious times.

Find a source of support, such as a family member, friend, and/or other young women who have been through the same experience. If you feel that you need professional help, you can ask your physician or nurse to recommend a psychiatrist, counselor, social worker, or other mental health professional.

You also may wish to communicate with other women who are going through the same experience. If you are participating in a program for high-risk women, you may have access to a support group of women who have had risk-reducing surgery, or at least to individuals who might be willing to talk about how they coped. Another option is to turn to the Web site of an organization called FORCE, or Facing Our Risk of Cancer Empowered (www.facingourrisk.org), which is designed specifically for women who are considered to be at higher than average risk for breast and/or ovarian cancer. An online message board allows women to share their experiences.

[Sidebar:

My Experience

"I think the surgery means different things to different women. I was 48, I wasn't going to have children at that point, and I knew that these organs weren't the sum total of who I was. I wasn't really losing anything, and I wasn't going to feel empty or incomplete once it was over. My attitude was 'just get them out.'

But there are a lot of women out there who feel that the ability to have children or even having a uterus and ovaries helps to define who they are. For them the surgery has a much deeper emotional impact, and it can be heartbreaking.

So, I think you have to know yourself and make sure the emotional support is there if you think you might need it." —Kelly

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"Emotionally, the hardest thing for me about having risk-reducing surgery at age 42 was realizing that I would never be able to have children. I never had any and it just seemed so final, that it would never be a possibility. Certainly I knew this going into the surgery, but it was still difficult. And I felt I had to have the surgery not only because I was high-risk, but also because I was having problems with cysts.

I try to remind myself that there are children out there who need help, and I can make a difference in that way." —Dina

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"I found it very helpful to attend a support group for high-risk women, some of whom had the surgery and some who did not. And I remember one woman who had the surgery said she was very anxious afterwards. Being put into menopause right away brought out a number of stressors for her.

That showed me that I will have to go into surgery understanding how I am going to deal with the anxiety I might have. I will have to know how to ask for help." -Rose

For More Information about Menopause

American College of Obstetricians and Gynecologists
(202) 638-5577
www.acog.org

The National Women's Health Information Center
1-800-994-WOMAN
www.4woman.gov

National Women's Health Resource Center
1-877-986-9472
www.healthywomen.org

The North American Menopause Society
(440) 442-7550
info@menopause.org
www.menopause.org

Long-Term Considerations

Going through menopause is known to increase a woman's risk for developing osteoporosis, a progressive thinning and weakening of the bones. It also may increase the long-term risk of developing heart disease. For women who have surgically induced menopause before the typical age of natural menopause, these conditions are a special concern. You should be aware of these risks and discuss them with your physician.

As already mentioned, the most current research on hormone replacement therapy (HRT) has shown that it decreases a woman's risk of developing osteoporosis. However, it also suggests that HRT does not protect against cardiovascular disease, as previously thought. This section will discuss the non-hormonal strategies that can be used to reduce these risks.

Another important long-term consideration is the risk of developing primary peritoneal cancer, an ovarian-cancer-like illness that originates in the peritoneum (the membrane that lines the pelvic cavity). Regular follow-up with your physician is essential.

Osteoporosis

Osteoporosis is a serious condition that, over time, can lead the bones to fracture quite easily, with just the smallest amount of force. The condition is much more common in women than men, and particularly in women with the following risk factors:

- A small, thin body frame
- Being of Caucasian or Asian descent
- A family history of osteoporosis

- Poor calcium intake
- Sedentary lifestyle (lots of sitting, little exercise)
- Smoking
- Excessive alcohol use.

You and your physician should discuss these risk factors in relation to the fact that you are already at increased risk, due to having undergone risk-reducing surgery. Although you cannot change your body type, ethnic background, or family history, there are ways that you can protect yourself against osteoporosis and detect any loss in bone density before it becomes serious enough to cause problems.

Diet and Lifestyle

A number of diet and lifestyle changes can be very helpful in preventing osteoporosis.

- **Increase calcium intake:** You need about 1,200 to 1,500 milligrams of calcium per day. The best sources include dairy products such as milk, cheese, yogurt, and green leafy vegetables. If you are not getting enough calcium in your diet, consider taking a daily calcium supplement.
- **Increase Vitamin D intake:** Vitamin D is essential for healthy bones because it aids in their absorption of calcium. You should consider taking a multi-vitamin that includes vitamin D, or increase the amount of vitamin D in your diet. Sources include vitamin-D fortified milk and cereals, egg yolks, saltwater fish, and liver.
- **Incorporate weight-bearing exercise:** Weight-bearing exercise is any kind of exercise in which the bones and muscles work against gravity as the feet and legs bear the body's weight. Examples include walking, jogging, Tai-Chi, stair climbing, dancing, and tennis. At minimum, you should be doing some form of weight-bearing exercise for at least 30 minutes per day, three times a week.
- **Quit smoking/ limit alcohol:** Quitting smoking and limiting alcohol intake also can help to reduce your risk of osteoporosis.

Bone Density Testing

It's also a good idea to have a bone density test to establish a baseline against which future tests can be compared. If you and your physician notice a significant drop in bone density at any point, you may wish to consider taking some form of medication to counteract this (discussed in the next section).

A dual energy X-ray absorptiometry scan, better known as a DEXA scan, is a test used to measure bone density in the spine, hip, and/or wrist. The test can be completed in about 15 minutes with very low radiation exposure (much less than that of a standard X-ray). Your DEXA test results will tell you how your bone density compares with that of "young normal" women (this is called your T-score) and with healthy women of your age (Z-score). These scores tend to decline with the steady drop in bone mass that tends to occur after menopause.

Another test that is sometimes used is heel ultrasound, which involves placing your heel into a machine that uses high-pitched sound waves to measure bone density. While it is not as thorough as a DEXA scan, it has proven useful in assessing a person's risk of osteoporosis. If your results suggest there is a problem, you can ask your physician about having the more thorough DEXA scan.

The National Osteoporosis Foundation recommends that therapy to reduce fracture risk should be started in women with:

- T-scores below -2.0, as measured by central DXA of the hip and/or spine, with no other risk factors
- T-scores below -1.5, with one or more risk factors

- A prior vertebral or hip fracture.

Medications

If necessary, there are medications you can take to prevent and treat bone loss. These include:

- **Bisphosphonates:** Better known by brand names such as Fosamax® and Actonel®, bisphosphonates help to prevent the breakdown of bone. Stomach upset is a common side effect, however, so they have to be taken according to directions.
- **Raloxifene (Evista®):** This medication is a type of selective estrogen response modulator (SERM), which means that it has estrogen-like effects on the bone but not on other parts of the body. It does not appear to increase the risk of breast cancer and uterine cancer, as estrogen does. It is approved by the Food and Drug Administration for the prevention and treatment of osteoporosis. Hot flashes are a common side effect of raloxifene.
- **Calcitonin medication:** Calcitonin is a hormone that is secreted by the thyroid gland and increases the level of calcium in the bones. Calcitonin medications, which are taken in the form of a nasal spray or by injection, are designed to mimic the action of natural calcitonin. They are used to treat osteoporosis and prevent it from worsening. It is generally safe and well-tolerated, although some people experience cold symptoms (runny nose) and, rarely, nosebleeds.

[Sidebar:]

My Experience

"I did discuss osteoporosis risk with my gynecologist. After the surgery I had a baseline DEXA scan. They want me to come back in two years for another test, to see if any changes have occurred." -Theresa

Heart Disease

Heart disease occurs when the blood vessels that feed the heart become clogged with plaque (so-called "hardening of the arteries"), increasing a person's risk of having a heart attack. Some studies have suggested that estrogen plays an important role in keeping women's arteries healthy. That is why physicians traditionally thought that hormone replacement therapy could decrease a woman's risk of developing heart disease after menopause. However, as already mentioned, the recent Women's Health Initiative study on HRT has challenged that belief (see the earlier section, "Loss of Estrogen").

Until the role of estrogen in heart health becomes clearer, you should assume that the removal of your ovaries has put you at increased risk of heart disease, just like all other post-menopausal women. You should have your cholesterol and blood pressure levels checked regularly, if you are not doing so already, and investigate whether your family history puts you at increased risk. You also can make a number of lifestyle changes as needed:

- Maintain a healthy weight
- Eat a healthy, low-fat diet rich in fruit and vegetables
- Quit smoking and limit alcohol intake
- Exercise regularly, incorporating at least 30 minutes of aerobic exercise three times per week.

If you have high cholesterol and/or high blood pressure readings even after making such lifestyle changes, talk to your physician about the possibility of taking medication to control your risk factors.

For More Information about Osteoporosis and Heart Disease

American Heart Association
1-800-AHA-USA-1 or 1-800-242-8721
www.americanheart.org

National Osteoporosis Foundation
(202) 223-2237
www.nof.org

Primary Peritoneal Cancer

Physicians do not have a reliable way of detecting primary peritoneal cancer early. You should see your gynecologist or gynecologic oncologist at least yearly for manual pelvic exams. You always should consult your physician if you experience any symptoms such as persistent bloating, upset stomach, pain, vaginal bleeding, or anything else that seems unusual, in the months and years after you have recovered from surgery.

[Sidebar:

My Experience

"Honestly, I felt a bit like I was in no-man's land after the surgery. For so long I had had a CA-125 test or transvaginal ultrasound every six months. The only follow-up I have now is that I go for pelvic exams every six months and a mammogram once per year. For me, it took some getting used to." -Agnes

QUESTIONS TO ASK . . . About the Side Effects of Risk-Reducing Surgery

As you plan to meet with the physicians who will perform your surgery and/or manage your follow-up care, you may want to ask about the following:

1. In your experience with your own patients, what are all the common side effects of risk-reducing surgery?
2. How do you typically manage these side effects?
3. If I feel that I need to consult with additional medical specialists, will you be able to provide me with referrals?

4. Are any of your patients who had the surgery willing to speak about their experiences with side effects? If so, can you put me in touch with them?

Draft

Section 4: If You Do Not Want to Have Surgery Right Now: What You Need to Know

You might decide that risk-reducing surgery is not the right choice for you at this time in your life. Perhaps you are much younger than your relatives were when they developed ovarian cancer, and you feel that you can put off the surgery until you get a little bit older. Or maybe you are hopeful that researchers will soon discover an accurate early detection test for ovarian cancer.

Even though risk-reducing surgery is the only proven option for greatly reducing ovarian cancer risk, there are other options you may wish to consider. These include:

- other prevention options: **taking oral contraceptives** or **undergoing tubal ligation** to reduce risk
- **undergoing close surveillance by a health care team** to increase the chance that ovarian cancer will be caught early if it does develop
- **participating in clinical trials** of new early detection methods.

Keep in mind that, for some women, deciding not to have risk-reducing surgery also means having to live with more cancer-related anxiety and uncertainty.

Symptoms of Ovarian Cancer

If you experience one or more of the following symptoms for more than a few days, be sure to see your doctor, and make sure that he or she knows you are at higher-than-normal risk of ovarian cancer.

- A feeling of being bloated or noticing that clothes don't fit as well as they once did
- Vague abdominal pain and pelvic discomfort
- Unexplained fatigue or back pain
- Gastrointestinal symptoms, such as gas and indigestion that persist over time
- A frequent urge to urinate
- A change in bowel habits
- Unusual bleeding or discharge
- Loss of appetite and feeling full even after a light meal
- Unusual weight gain or loss
- Pain during intercourse
- Shortness of breath.

Other Prevention Options

Taking Oral Contraceptives

Some studies have shown that women who take oral contraceptives before menopause can decrease their risk of ovarian cancer by as much as 50 or 60 percent. The theory is that, by preventing ovulation, oral contraceptives also prevent the damage to the wall of the ovary (or epithelium) caused by the monthly release of the egg. Physicians often recommend them as a strategy for high-risk women who desire a non-surgical preventive measure.

One study of women considered to be high-risk for ovarian cancer found that history of oral contraceptive use could reduce that risk. The study enrolled 207 women with hereditary ovarian cancer, all of whom had a BRCA mutation, and 161 of their sisters, and asked them about oral contraceptive use. Any past use of contraceptives was associated with a 50-percent reduction in ovarian cancer risk. Use for six or more years was associated with a 60-percent reduction in risk.⁸

Oral contraceptives do entail some risks of their own, such as blood clots and stroke, so you will need to make this decision in close consultation with your physician.

Tubal Ligation

Tubal ligation, a surgical procedure better known as “tying the tubes,” is a permanent form of birth control. Performed laparoscopically, it involves sealing or clipping the fallopian tubes, the tubes that connect the ovaries to the uterus. This prevents any eggs from making their way into the uterus, where they could be fertilized by sperm. The ovaries continue to produce eggs and the hormone estrogen until the woman goes through menopause naturally.

Research suggests that tubal ligation reduces ovarian cancer risk. Current theory holds that this procedure protects the ovaries from contaminants that could travel into the body through the vagina, into the cervix and uterus, and through the fallopian tubes into the ovaries. However, more research is needed before this mechanism will be fully understood.

One study involving nearly 500 women with BRCA mutations, half of whom had a history of ovarian cancer and half not, suggested that tubal ligation affords some protection for BRCA1 mutation carriers. Researchers found that 18 percent of the women who developed ovarian cancer had undergone a tubal ligation, while 35 percent of the women who had not developed cancer had the procedure. The effect was even more pronounced when tubal ligation was combined with oral contraceptive use.⁹

Like any surgery, tubal ligation does involve some risk, and it is appropriate only for women who are sure they have completed childbearing. However, it may be an option for you if you are interested in permanent contraception that could also help to reduce your ovarian cancer risk.

Close Surveillance by a Health Care Team

Close medical surveillance simply means undergoing regular screening and physical examinations in the hope of detecting ovarian cancer at an early stage, when it is most curable.

If at all possible, it is a good idea to have this aspect of your care managed by a health care team experienced in working with women at increased risk. They will have more experience in detecting ovarian cancer through the use of clinical exams and blood and imaging tests. Work with the team to come up with a schedule for regular testing. The following recommendations are pretty typical, although they can vary from physician to physician. If you need help finding experts for this type of care, see the suggestions in the box below.

- **Bimanual pelvic examination, every six to 12 months:** “Bimanual” means that the practitioner uses two hands, one placed inside the vagina and the other placed outside on the abdomen, in an attempt to feel the ovaries for any abnormalities.

⁸ Narod SA, Risch H, Moslehi R, et. al. “Oral contraceptives and the risk of hereditary ovarian cancer. Hereditary Ovarian Cancer Clinical Study Group.” *New England Journal of Medicine* 1998 Aug 13; 339(7): 424-8.

⁹ Narod SA, Sun P, Ghadirian P, Lynch H, Isaacs C, Garber J, Weber B, Karlan B, Fishman D, Rosen B, Tung N, Neuhausen SL. “Tubal ligation and risk of ovarian cancer in carriers of BRCA1 or BRCA2 mutations: a case-control study.” *Lancet* 2001 May 12; 357(9267):1467-70.

- **CA-125 measurement, every six to 12 months:** CA-125, a protein in the blood, is often elevated in the presence of ovarian cancer (a level of 35 or lower is generally considered “normal”). However, this is not a perfect test: often it is not elevated when the cancer is at an early stage, and for some women it does not become elevated at all.
- **Pelvic ultrasound, every six to 12 months:** During this test, the technician places a sound-emitting probe into the vagina. The sound is too high-pitched for you to hear, but the waves will bounce off the nearby structures to create images on a specialized computer screen. The results can help the health care team determine whether there is any unusual growth on the ovaries.

Right now, pelvic ultrasonography is the most sensitive method for early detection of ovarian tumors, but it is not a perfect test. It may fail to pick up early-stage tumors, and even the most skilled experts reading the results can miss a cancerous tumor. In other cases, the test may suggest an abnormality that leads a physician to perform surgery – only to find that cancer is not present.

Finding an Experienced Health Care Team

It's important to work with a health care team that has experience in managing women who are considered high-risk for ovarian cancer.

**National Cancer Institute
Cancer Genetics Services Directory**
1-800-4-CANCER

www.cancer.gov/search/genetics_services/

A directory of individuals who provide services related to cancer genetics (cancer risk assessment, genetic counseling, genetic susceptibility testing, and others). Many are affiliated with programs for high-risk women at hospitals and cancer centers nationwide.

[Sidebar:]

My Experience

“I joined a program specifically for high-risk women at a cancer center. When I decided not to have risk-reducing surgery, my doctors recommended alternating a mammogram and transvaginal ultrasound every six months. They also recommended CA-125 testing every year. A few years ago, I joined a special study that requires getting my CA-125 tested four times per year, not one. If they find a result that is above the baseline or above what has been normal for you, they send you for a precautionary transvaginal ultrasound.

Every six months, I meet with the doctor and nurse to update my family history, get a manual breast exam, and basically talk about anything new in the research findings and my current thinking. They tell me what options I have to choose from.

I would recommend that any woman in a genetic high-risk group join a program like this if she can. You get to develop a personal relationship with the doctors and nurses on staff, and there is always someone knowledgeable to talk to. I think it's important to go down this road with someone who understands your history.”
-Rose

8

“Knowing that I can go somewhere regularly and have blood drawn for a CA-125 test, have a mammogram, have my breasts checked by a trained physician – these things give me peace of mind. Are these the greatest tests in

the world? No. Is there a chance that something could be missed? Absolutely. It's not an exact science, that's for sure. But it still it makes me feel better, even though it may be a false sense of security." -Donna

Participating in Research on Early Detection

Early detection is one of the more active areas in ovarian cancer research. Researchers know that they can help many more women survive this disease if they can just develop a reliable screening test that would detect it at its earliest, most curable stage, before symptoms develop. The test has to be specific for ovarian cancer: in other words, it must minimize the number of false positives (that is, the number of women who test positive but do not actually have ovarian cancer) and false negatives (the number of women with a negative result who really do have cancer). Because the screening tests now available have limitations, this is a much-needed area of research.

The Limits of CA-125: False Positives and False Negatives

CA-125 is a protein that has been found to be elevated in roughly 80 percent of women with ovarian cancer. The protein is produced on the surface of ovarian cancer cells and released into the bloodstream. Generally, values from 0 to 35 units per milliliter are considered normal. "Normal" varies from woman to woman, though, leading to the problem of "false" or misleading test results.

False positive

A false positive occurs when a woman's CA-125 level is over 35, but she does not have ovarian cancer. An elevated CA-125 is also associated with a number of other conditions besides ovarian cancer, such as benign ovarian tumors, endometriosis, pelvic inflammatory disease, uterine fibroids, liver disease, pancreatitis, kidney problems, heart failure, pregnancy, and menstruation. For a woman considered to be at high-risk of ovarian cancer, a false positive can lead to unnecessary surgery and intense anxiety.

False negative

A false negative occurs when a woman's CA-125 level is normal, but she does have ovarian cancer. About 95 percent of women with advanced stage disease (stage III or IV) have an elevated CA-125, but only 40 to 50 percent of women at stage I do. Therefore, there is a chance that a woman with a normal reading could have ovarian cancer, most likely in its early stages. Thus, a false negative could give a woman a false sense of security, even when she has ovarian cancer.

If you have not already done so, you and your family members may wish to investigate the possibility of enrolling in a cancer risk assessment program. Doing so may give you access to special surveillance programs and clinical trials for women with positive mutations and/or strong family histories. Clinical research studies evaluate new and potentially more effective approaches to detecting ovarian cancer.

A number of clinical trials enroll high-risk women (and in some cases, women at average risk as well) to evaluate new ways of detecting ovarian cancer early. Typically, these may include:

- new blood tests that can replace that CA-125
- newer, more accurate imaging tests.

Because so much is yet to be learned about how to help women who are considered high-risk for ovarian and breast cancer, you and your family members may wish to investigate the possibility of enrolling with a cancer risk assessment program that gives you access to specialized care, surveillance programs, and clinical trials for women with positive mutations and/or strong family histories.

[Sidebar:

My Experience

"I am taking part in two risk assessment studies, as is my sister. I have children — a son and a daughter — and in my mind and heart I know I owe it to them to participate. I might have passed the mutation on to them. Anything I can do to help researchers better understand genetic risk or improve the testing will be worth it in the long run. If the research won't help me, it could help them." -Donna

Finding Clinical Trials

If you find a program for high-risk women at a hospital or cancer center in your area, the staff should be able to tell you about any clinical trials or research programs for which you may be eligible. If you want to conduct searches on your own, a good starting point is the clinical trials section of the National Cancer Institute Web site, at www.cancer.gov/clinical_trials. The database allows you to limit your search according to a number of different criteria, including cancer type, type of trial (in your case, a screening trial), and location. The same clinical trials are also accessible through the National Institutes of Health database at www.clinicaltrials.gov. All of these trials are either sponsored by or approved by the National Cancer Institute.

See the boxed feature for listings of these and other online clinical trials databases, some of which are hosted by private companies. While you may find some overlap between government and private databases, the latter may lead you to other trials sponsored by pharmaceutical and biotechnology companies. Keep in mind that as current trials complete their enrollments, new trials may be opening up.

Some women find that participating in a clinical trial alleviates some of their cancer-related anxiety and gives them a greater sense of control. Also, they like the fact that they tend to be monitored more closely on a trial than they would be otherwise.

Resources for Finding Clinical Trials

Acurian
(215) 675-6100
www.acurian.com

CenterWatch
(617) 856-5900
www.centerwatch.com

National Cancer Institute
1-800-4-CANCER
www.cancer.gov/clinical_trials

National Institutes of Health
www.clinicaltrials.gov

National Ovarian Cancer Coalition
1-888-OVARIAN
www.ovarian.org

Emotional Considerations

It can be a relief not to have to deal with the short-term pain and limitation associated with risk-reducing surgery, nor with longer-term effects due to surgical menopause. This is perhaps the greatest emotional benefit of deciding not to have surgery. At the same time, however, you could experience some anxiety as a result of your decision.

You will be living with the knowledge that you remain at higher-than-average risk for ovarian cancer. Your anxiety may be intensified by the knowledge that ovarian cancer is very difficult to detect early, even when a woman is being followed closely by her doctor. Also, if you undergo regular CA-125 testing and ultrasounds, you could at some point receive a false positive result – a result that suggests the possibility of ovarian cancer even when it really is not present. This is likely to cause you and your loved ones a significant amount of anxiety. You also could receive a false negative result: that is, everything seems normal on testing, even when an early-stage cancer is present. This realization also may cause you some anxiety.

In addition, your partner, family members, other loved ones, and even your physician may disagree with your decision. Naturally, these people want to protect you from ovarian cancer, and they may see risk-reducing surgery as the best option for doing so. They may not be as convinced as you are by your reasons for deciding against surgery. Also, you may have relatives who are also high-risk and have decided to go ahead with the surgery – and this may cause some tension in your relationships.

Of course, every woman's situation and feelings can be a little bit different. You may find it helpful to talk to your health care team about these issues, or ask them to put you in touch with a social worker or mental health provider who can help you sort through them.

You also may wish to communicate with other women who are going through the same experience. If you are participating in a program for high-risk women, you may have access to a support group of women who have had risk-reducing surgery, or at least to individuals who might be willing to talk about how they coped. Another option is to turn to the Web site of an organization called FORCE, or Facing Our Risk of Cancer Empowered (www.facingourrisk.org), which is designed specifically for women who are considered to be at higher than average risk for breast and/or ovarian cancer. An online message board allows women to share their experiences.

[Sidebar:

My Experience

"I have been pretty good at controlling anxiety and keeping the knowledge that I am high-risk 'compartmentalized' in my mind. Now that I am in perimenopause I would say that I am experiencing a bit more anxiety.

I don't know if it's due more to the start of menopause, or to the thought that, 'Wow, I really might develop breast cancer or ovarian cancer.' I have seen it all: I watched my mother go through breast cancer, my cousin go through breast and ovarian, a girlfriend go through breast cancer. I know what it looks like and it is not pretty. It is difficult to see someone go through it and not be able to survive it.

I would put my anxiety on a low scale, but it is creeping into my thoughts more and more." —Rose

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"I have to say I can count on two or three fingers any times when I have felt panicked or scared about my decision not have risk-reducing surgery. I don't spend a lot of time thinking that way — it's just not healthy. I will admit that there was a time when I was frantic about all of this, and I don't know why I kept doing that to myself.

I feel so good that it is so hard for me to imagine going through an elective surgery that could potentially worsen my quality of life. Even though I might change my decision at some point, for right now in my life I have made the right decision for me. And that gives me the most satisfaction." -Donna

SUMMARY | Advantages and Disadvantages of Not Having Risk-Reducing Surgery

ADVANTAGES

- Women who choose not to have risk-reducing surgery maintain their fertility and avoid sexual aide effects and surgical menopause.
- Women also avoid the short-term pain, inconvenience, and risk of complications associated with any surgical procedure.

DISADVANTAGES

- Women will need to consider other options to reduce their risk of, and screen for, ovarian cancer. All of these options have limitations.
- Not having surgery may mean living with more cancer-related anxiety.

QUESTIONS TO ASK . . . If You Decide Not to Have Risk-Reducing Surgery Now

These questions may help you when talking with your physician:

1. How much experience have you had managing women who are at higher-than-average risk of developing ovarian and breast cancer? In your experience, what are the most pressing issues they confront if they decide not to have risk-reducing surgery?
2. If you have not had much experience in this area, can you refer me to someone who has?
3. How would we work together to manage my care? Would you manage all aspects of that care, or would you prefer that I see another physician as well? How would the two of you communicate?
4. What tests would you recommend, and how often? If I want to see you or be tested more frequently than you recommend, would you be able to accommodate me?

5. Am I am potential candidate for any clinical trials on early detection of ovarian cancer? If so, can you help put me in touch with the right contact person?
6. Would you recommend that I take oral contraceptives? Why or why not?
7. What should I do if I have problems or questions in between visits? Will you be able to field my questions?
8. Is there anything else I should be thinking about in relation to my decision not to have risk-reducing surgery?

Draft

Section 5: Sexuality and Intimate Relationships after Risk-Reducing Surgery

It is important to give some thought to how risk-reducing surgery could affect your relationship with a current – or future – partner or spouse. In general, the issues are similar whether you are in a relationship with a man or a woman. Certainly, the reduction in cancer-related anxiety can benefit physical and emotional relationships, freeing you and your partner to focus less on the question of “What if?” and more on your future plans and your life together. Some women in heterosexual relationships find that freedom from using birth control also improves their sex lives.

At the same time, many women who have risk-reducing surgery report that they experience sexual side effects such as vaginal dryness and discomfort, as well as a decrease in their libido, or sex drive. They find that intercourse is uncomfortable, unappealing, or just “different” than it used to be. Other physical effects of surgery, such as fatigue and hot flashes, can interfere with sexual desire.

Before considering the potential impact of risk-reducing surgery on sexuality and intimate relationships, however, it's important to think more broadly about your own sexuality. This is a complex subject, and there are many factors involved in intimacy besides hormones and sex organs.

Thinking about Sexuality

When you hear the word “intimacy,” it may bring to mind images of warm affection, closeness, and caring – perhaps in the context of lovemaking but perhaps not.

Your sexuality certainly has a physical component influenced by hormones and body image – how you see your body and how satisfied you are with it. But sexuality is much more than the experience of orgasm or intercourse. The physical part is balanced by your emotional health, which is influenced by current or past issues and events. Your concern about your risk of cancer could be one of these issues. Factors such as your feeling of well-being, sense of usefulness and meaning in life, and the depth of commitment and support in close relationships can all have an impact. Just as these factors can vary over time, variations in sexual interest occur normally over our lifetime and don't necessarily mean there's a problem. (See the boxed information below if you wish to read more on this topic.)

It's also important to realize that many people and their healthcare providers don't feel comfortable discussing sexual issues. You may find that it takes courage to bring up sometimes awkward and embarrassing topics with your healthcare team and your partner. It also may require the patience to start slowly and work on these issues at a pace that feels right to you. While it may be difficult, talking about potential sexual side effects of ovary removal sooner rather than later is likely to help. Things may not be exactly the way they were, but you can find a “new normal” that satisfies you and your partner. This section is designed to help get you started.

For More Information about Sexuality

Andrew Goldstein, M.D. and Marianne Brandon, Ph.D. *Reclaiming Desire: 4 Keys to Finding Your Lost Libido*. Emmaus, PA: Rodale Press, 2004.

National Women's Health Report, April 2005 issue on women's sexual health. Available at www.healthywomen.org/Documents/NationalWomensHealthReport.April2005.pdf.

Get Educated and Plan Ahead

You can certainly have an enjoyable sex life again after risk-reducing surgery. Whether you had just your ovaries removed, or you had your uterus and/or cervix removed as well, you still have your vagina and clitoris — both of which play a central role in sexual pleasure and functioning. The breasts, skin, and brain are other organs that contribute to arousal and pleasure.

We encourage you to spend time thinking about the sexual practices of you and your partner. Then consider the possible sexual side effects of surgery in the following section. Think about the adjustments you may need to make, how that may make you feel, and what support you might need.

The Impact of Surgery on Your Sex Life

Depending on the extent of your surgery and your own doctor's recommendations, you'll need at least two to four weeks for healing before having intercourse. More details about types of surgery and the recovery period are found in Section 3.

Like the symptoms of surgical menopause already discussed, sexual side effects are due, at least in part, to the sudden drop in hormone levels that occurs when the ovaries are removed. In addition to producing estrogen and progesterone, the ovaries produce testosterone, which many people think of as a male hormone but also is present in women and believed to play an important role in sexual desire.

This drop in hormone levels can cause some physical changes in pre-menopausal women. Blood flow to the vagina and clitoris decreases, and this in turn decreases vaginal lubrication. There's also a thinning of the tissue lining the vagina. These changes can make intercourse uncomfortable. There also can be decreased sensitivity and lessened quantity and strength of orgasms.

Wrapped up with the physical changes you may experience is the potential impact of your surgery on libido or sex drive. This is a challenging subject because women's sexual desire is quite complex. In a special issue of the *National Women's Health Report* focused on women's sexual health (National Women's Health Resource Center, April 2005), Sheryl A. Kingsberg, Ph.D., a reproductive biology and psychiatry professor at Case Western Reserve University, notes that women's libido involves three components:

- The physical or biologic part
- Social beliefs and values
- Motivation.

Risk-reducing surgery can affect all three areas in different ways. For example, lower levels of hormones can lessen sex drive, as can physical side effects such as vaginal dryness and discomfort. These also can make you feel less motivated to have sex. If you have always thought of menopausal women as "non-sexual" (a social value), then being in menopause may lead you to think of yourself that way. And if you are feeling sad, anxious, or fatigued after surgery, certainly this can affect your motivation to have sex. On the other hand, you may experience an emotional lift after surgery, and this can improve sexual motivation.

When it comes to research, relatively little is known about how to improve a woman's libido — and even less is known about how to improve it after surgical menopause. Because this field of study is so new and not often discussed openly, many of the potential treatments discussed in this section have neither been tested rigorously nor approved by the Food and Drug Administration. Low libido is one of many sexual side effects that are addressed below.

Managing Sexual Side Effects

There are a number of different strategies that have helped women to manage the physical changes after ovary removal. We discuss them below in no particular order of preference.

Hormonal Treatments

Section 3 discussed hormone replacement therapy (HRT) as a possible treatment for symptoms of surgical menopause. HRT also can help with the vaginal dryness and discomfort that make sex uncomfortable for some women. However, as already noted, research has raised some concerns about giving HRT to women who are considered high-risk for developing breast and ovarian cancer. This decision needs to be made on a case-by-case basis and requires close consultation between a woman and her physician.

Other hormonal options include:

- **Estrogen creams, tablets, or rings:** Estrogen applied directly to the vagina can help make sex more comfortable and pleasurable. Estrogen is available as a cream (Estrace®), as a tablet that can be inserted into the vagina (Vagifem®) once daily for two weeks and then twice a week thereafter, and as a ring that can be placed in the vagina for up to three months (Estring®). The tablet and ring products are considered safe compared to oral HRT because the estrogen does not travel throughout the body. Small amounts of Estrace cream have been shown to be absorbed into the bloodstream.
- **Testosterone patch:** The hormone testosterone is made by the ovaries and thought to play a role in a woman's sex drive. Some women have been helped by using a testosterone patch placed on the skin to deliver low doses of the hormone to the body. A patch called Intrinsa® underwent review by the Food and Drug Administration in 2004, but the FDA concluded that the product needed more safety data before it could be approved. There have been reports that some women experience side effects such as facial hair growth and voice changes. Nevertheless, many doctors will make the patch available to women complaining of low libido. Testosterone also comes in the form of a gel or cream that can be applied directly to the skin.

Lubricants and Moisturizers

Applying lubricants and moisturizers outside and inside the vagina can help to relieve the problems of vaginal discomfort and dryness. Water-based lubricants such as Astroglide® and K-Y Liquid® are intended to be used during intercourse to replace diminished vaginal secretions. Some brands offer a version that provides a warming sensation on contact, which may further help with sexual stimulation. Vaginal moisturizers such as Replens® and Lubrin® are used on a regular basis to keep the vagina moist for a longer period and relieve ongoing irritation. These too can help to prevent discomfort during intercourse.

A newer product called Zestra®, which is advertised as "feminine arousal fluid," consists of a blend of botanical oils. It is designed to increase lubrication and intensify a woman's climax. Other creams such as Viacreme®, Vigel®, and Femore® also claim to increase feelings of arousal, although none has undergone rigorous clinical testing. Your healthcare professional may be able to give guidance on use of these products, as the safety profile is not well established.

Alprostadil, which traditionally has been used in men to increase blood flow to the penis, is being studied in women. In research studies it increased feelings of arousal and pleasure when applied to the clitoris and vagina.

External and Internal Devices

Some women find that the vagina shrinks after surgery, making intercourse uncomfortable or even painful. Regular use of a vaginal dilator or a dildo (an object shaped like an erect penis) can help to widen the vagina.

Other devices can be used to increase blood flow to and stimulation of the clitoris, which can produce more vaginal lubrication and feelings of arousal. One is the EROS Clitoral Therapy Device, a vacuum-pump device applied directly to the clitoris and vagina to increase blood flow to the area. It is approved by the FDA and available by prescription. Another is the standard vibrator, which is used to stimulate the clitoris. If you feel uncomfortable purchasing a vibrator, take a friend with you for moral support or trying shopping online. Many online stores will send the item to you in discreet packaging that gives no indication of the contents.

Medications

No medications have yet been approved to treat problems with arousal in women. Some studies have suggested that medications used to treat impotence in men, such as Viagra®, also can help women become more sexually aroused. Just as they increase blood flow to the penis in men, they also increase flow to the clitoris in women. Pills with names such as ArginMax® and Avlimil® are advertised with claims that they can improve sexual function in women, but these have not been proven in scientific studies.

Be sure to check with your physician before taking any medication without a prescription.

Changing Your Sexual Routines

When it comes to sexual behavior, many couples tend to fall into routines, especially if they have been together for a long time. You may need some adjustments to help you feel more inclined toward reestablishing your intimate relationship and becoming sexually active again.

While little advice has been written specifically for women undergoing risk-reducing surgery, more has been written for survivors of breast and ovarian cancer, whose libido is often affected by chemotherapy and/or surgical removal of the ovaries. In her book *Sexuality and Fertility After Cancer*, for example, Leslie R. Schover, Ph.D., recommends abandoning what she calls the "performance model" of sex — that is, the image of easy, perfectly satisfying sex perpetuated on movies and television. She stresses that intimacy can take a range of forms, from a romantic dinner or dancing to kissing and touching. These activities may or may not lead to intercourse, but they can help to reestablish a sense of intimacy.

You also may have to ask your partner to spend more time on foreplay. This helps to bring about the sense of arousal that causes the vagina to relax, widen, and lengthen, and also become more lubricated in preparation for intercourse (if you normally engage in intercourse). You also may find that manual or oral stimulation of the clitoris and vagina is more pleasurable than vaginal intercourse — or perhaps a good lead-in to intercourse.

If you had a hysterectomy in addition to oophorectomy, you may also find that sex feels different because you are different anatomically. You will no longer have a uterus and, in many cases, a cervix. Some women report that orgasms feel different as a result; the contractions of the uterus that may have been part of the experience may no longer be there. You will still have your clitoris and vagina, however, and these may become more central to your sexual experience than they were before.

[Sidebar:]

My Experience

"I was very worried about the sexual changes I was going to face from my oophorectomy. I was only 48 and not through menopause and I was worried that our relationship would be different and not fulfilling if my sex interest or ability changed. My husband assured me that sex was only the icing on the cake of our relationship. His telling me how important I was in his life built a stronger bond of intimacy. Our facing this together brought us so much closer." -Grace

§

"I'm a divorced mother of two and I don't really have a significant other, nor am I looking for one. Raising my kids is my first priority, so loss of libido and vaginal dryness are not things I have really worried about at this stage in my life. Ten years from now when they are grown and out of the house, maybe I'll be thinking about it, but not right now." -Theresa

§

"The potential impact of surgical menopause on intimate relationships was definitely a factor in my decision not to have the surgery right now, at age 42. I may change my mind later in life, but for now I am keeping my ovaries." -Donna

§

"I had gone through menopause before I had the oophorectomy. My husband and I had already faced some changes in our sex life just from my menopause. I saw that I was not as interested in sexual intercourse as often as he was. We worked things out between us, trying different things besides sexual intercourse to meet both our needs. So when it came to having the oophorectomy, I had no problem." -Sally

Involve Your Partner

If you are currently in a relationship, spend some time talking with your partner about how things are going now and what changes risk-reducing surgery might cause — both in your intimate relationship and your relationship overall, since these tend to go hand-in-hand. A healthy day-to-day relationship often translates into a healthy intimate relationship, and vice versa.

Some questions you may wish to discuss together include:

- **How have we weathered other difficulties in our relationship?** If you have a good track record, then the same skills will prove useful at this time. On the other hand, if you find it hard to deal with other sources of stress besides those of everyday life, you may need to work on improving this aspect of your relationship before having surgery.
- **How is our relationship right now?** Whatever is going on right now could be compounded after risk-reducing surgery. If you are having problems, particularly in areas such as communication and sexual intimacy, these could worsen after surgery.
- **Is the timing right for us as a couple?** If you have young children, demanding jobs, or other commitments, you will need to consider these in making your decision. Can your partner take on more responsibilities at home while you recover? Will he or she do this willingly, or will this become a source of resentment?
- **How is our sex life now and how will we deal if it changes?** Will you be able to discuss this with each other, and get additional help from a counselor or therapist if you need it? Are you willing to express intimacy in other ways and/or change your sexual routine, if needed?

If you are not currently in a relationship, you can adapt these questions to your situation now. How have you weathered difficulties on your own? How central is sex to your life? Are you dating now or do you wish to date in the future, and how will you cope with possible sexual side effects as you do so?

These are intended only as a starting point. Brainstorm your own list of questions and share them with your partner. If you're not accustomed to communicating in this way, break the ice by sharing this booklet – especially the parts about the potential consequences of surgery. Let your partner know you understand that surgery will impact both of you as a couple, and make it clear that you want to deal with these issues up front.

[Sidebar:]

The Partner's Experience

"Surgery has definitely affected our relationship. Immediately after surgery, she found that her sex drive decreased. A little while ago, she switched a medication that she's on, and that decreased her desire even more. But we're working through it together, even though the desire for sex isn't always there." -Eric

80

"We're having less intimate contact than we had earlier in our relationship, but it's hard to tell whether that's due to the surgery or 20 years of marriage! We try to keep the lines of communication open." -Joe

80

"Our sexual relationship has always included a lot of touching, kissing, and holding each other. None of that has changed since my partner went through menopause as a result of the surgery." -Connie

80

"The surgery has affected our relationship on many different levels. The physical consequences have tied up a lot of time and energy and attention and such, so that affects us in all sorts of ways. And some of those consequences affect our sex life pretty directly. My wife just had trouble with chronic urinary tract infections, and that certainly interfered with things." -Mark

80

"The effect on our intimate life wasn't a huge problem because sex wasn't playing as important a role in our relationship as it had when we were younger. I would say that our relationship is as intimate as it was 20 years ago, but the frequency of sex has certainly diminished over the years.

In a larger sense, I think the experience strengthened our relationship. It was our first really serious hurdle to conquer and instead of being negative, it really brought us closer to the realization of how human we are." -Timothy

Ask for Help

Many people have difficulty talking about issues related to sexuality and intimacy. Nevertheless, raising sexual concerns *before* risk-reducing surgery will make it much easier to discuss them afterwards. The following questions are designed to get you started.

If necessary, consider the possibility of seeking professional help from a social worker, psychologist, psychiatrist, relationship therapist, or other type of relationship counselor. Your physician or nurse may be able to make recommendations. Also, the boxed resources list at the end of this section features contact information for a number of organizations that may be able to connect you with a qualified professional.

One other note: if you have been a victim of sexual abuse or other sexual trauma, you should consider seeking help from a mental health professional, such as a social worker, psychologist, psychiatrist, relationship therapist, or other type of counselor.

QUESTIONS TO ASK . . . About Sexuality and Intimacy after Surgery

These questions may help you (and your partner) when talking with your healthcare provider

1. How soon can I resume sexual relations after risk-reducing surgery?
2. Do you feel comfortable talking about possible sexual side effects and treating them if they should occur? If not, can you refer me to a specialist who can help me?
3. What do you typically recommend for women who report changes in their sexual functioning and libido after risk-reducing surgery?

For More Information about Sexuality

ORGANIZATIONS & WEB SITES

American Association of Sex Educators Counselors & Therapists (AASECT)

P.O.Box 1960
Ashland, VA 23005
(804) 752-0026
Email: aasect@aasect.org
www.aasect.org

American Association for Marriage and Family Therapy

112 South Alfred Street
Alexandria, VA 22314-3061
(703) 838-9808
www.aamft.org

Association of Reproductive Health Professionals

2401 Pennsylvania Avenue, NW
Suite 350
Washington, DC 20037
(202) 466-3825
www.arhp.org

"Nurture Your Nature: Inspiring Women's Sexual Wellness" Web site

www.nurtureournature.org

An informational resource developed by the Association of Reproductive Health Professionals and the National Women's Health Resource Center "in response to the gap in education about women's sexuality."

The Sexual Health Network

3 Mayflower Lane

Shelton, CT 06484

www.SexualHealth.com

The Womens's Sexual Health Foundation

Email: info@twshf.org

www.twshf.org

BOOKS

Andrew Goldstein, M.D. & Marianne Brandon, Ph.D. *Reclaiming Desire: 4 Keys to Finding Your Lost Libido*. Rodale, 2004.

Leslie R. Schover, Ph.D. *Sexuality and Fertility After Cancer*. New York: John Wiley and Sons, 1997.

Marisa C. Weiss, M.D., and Ellen Weiss. *Living Beyond Breast Cancer: A Survivor's Guide for When Treatment Ends and the Rest of Your Life Begins*. New York: Random House, 1997. See Chapter 12, "Intimacy, Sex, and Your Love Life."

A Decision-Making Tool

This worksheet is designed to help you move forward in making your decision about whether or not to have risk-reducing surgery for ovarian cancer, based on the information provided in this booklet. If you have already made your decision, it may help you to clarify the reasons behind it.

You may find it useful to discuss your answers with your healthcare team and with loved ones who are assisting you with your decision.

I. Personal Information

This section is a place to record information about yourself that may help you do the following:

- Define your risk of getting ovarian cancer
- Think through the implications of surgery related to fertility and menopause.

Defining Your Risk of Ovarian Cancer

For more information on defining your risk, see Sections 1 & 2 of this booklet.

Genetic Test Results

Fill in the appropriate boxes in the following chart to reflect your experiences with genetic testing to date.

Genes Tested	Date test done	Result? (check one)	Don't know the results (see your doctor)	Your understanding of what the results mean
BRCA1		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Inconclusive		
BRCA 2		<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Inconclusive		
HNPCC		<input type="checkbox"/> Positive <input type="checkbox"/> Negative		

		<input type="checkbox"/> Inconclusive		
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If you tested negative for the genetic mutations known to increase ovarian cancer risk, has your doctor said that you are at higher-than-average risk of ovarian cancer due to a strong family history?

Yes _____ No _____ Don't Know _____ (If you're uncertain, speak with your doctor.)

What This Means: A Note about Genetic Mutations, Family History, and Ovarian Cancer Risk

- Women with BRCA1 mutations have approximately a 40-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 18 percent to 54 percent.) Since a woman in the general population has just a two-percent chance of developing the disease (1 in 50), this means that a woman with a BRCA1 mutation is 20 times more likely to develop ovarian cancer.
- Women with BRCA2 mutations have approximately a 10-percent chance of developing ovarian cancer by age 70. (In individual studies, this chance ranged from 2.4 percent to 19 percent.) This means that a woman with a BRCA2 mutation is five times more likely to develop ovarian cancer than a woman in the general population.
- Estimates of HNPCC-related lifetime ovarian cancer risk vary, although one recent article estimates it at 12 percent. This means that women with an HNPCC mutation are roughly six times more likely to develop ovarian cancer than women in the general population.
- Women who do not have a mutation but do have strong family history (defined as one or more relatives who developed the disease) a lifetime risk of developing ovarian cancer that ranges from 5 to 11 percent.

[Sidebar box to summarize above information:]

Lifetime Risk of Ovarian Cancer for Women with . . .

BRCA1 mutation	18-54%
BRCA 2 mutation	2.4-19%
HNPCC-related mutations	12%
No mutations or family history (general population)	2%

Age and Family History

Your age: _____

What was the earliest age that ovarian cancer developed in one of your family members?

List here the names of family members with known or suspected ovarian cancer and the ages they were diagnosed.

Name	Relation to You	Age at Diagnosis

What This Means: A Note about Age and Family History as Risk Factors

- Simply getting older increases a woman's risk of ovarian cancer. In the general population, most cases are diagnosed after menopause (average age: 62). Women who are considered high-risk are more likely to develop the disease in their mid-40s and 50s – a full ten to 15 years earlier.
- For a woman with a strong family history, experts generally recommend that she compare her own age with the age at which her youngest relative developed ovarian cancer. While she always needs to be vigilant about her risk, it becomes especially important as she approaches that relative's age (within 10 years). For example, a woman in a family where ovarian cancer appeared at age 45 would want to step up her vigilance beginning at age 35.
- The greater the number of relatives diagnosed—and, more specifically, the greater the number of first-degree relatives (mother, sister, daughter) affected—the greater the risk.

Effect of Surgery on Fertility and Menopause

Fertility

Do you want to have children/ more children? _____

If "yes," you should give very serious thought to weighing this desire against the compelling reasons to have surgery. Removing your ovaries will take away your ability to get pregnant.

Menopause

Are you still having menstrual periods? ☐ Yes ☐ No

Having your ovaries removed before going through natural menopause (defined as being without menstrual periods for 12 months or longer) will cause immediate menopause with a number of possible physical and emotional effects. To read more about these effects, please see Sections 3 & 5.

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II. Weighing the Pros and Cons of Risk-Reducing Surgery

The following questions are meant to correspond with the information provided in Sections 2 and 5. You should review those sections if you require more background information about the reasons for and against having risk-reducing surgery for ovarian cancer.

The Status of Your Decision-Making

How soon would you like to make your decision? _____

(Often there is no definite deadline, but you may wish to set a date with your healthcare team if this is helpful to you.)

Which of the following statements best describes you at this point? Circle the best choice.

I have decided to have risk-reducing surgery for ovarian cancer.

I am pretty sure I will have risk-reducing surgery.

I am still unsure of my decision, but I am leaning toward risk-reducing surgery.

I am completely undecided about whether or not to have risk-reducing surgery.

I am still unsure of my decision, but I am leaning toward not having risk-reducing surgery.

I am pretty sure I will not have risk-reducing surgery.

I have decided not to have risk-reducing surgery.

In the space below, write down your most important reasons for this choice.

Reasons for Having Risk-Reducing Surgery

This guide has discussed a number of reasons why women choose to have risk-reducing surgery for ovarian cancer. Read through the following statements and decide how closely each one applies to you. Check the most appropriate box for each reason.

Considering your reaction to these statements may help you make a decision. If you find yourself agreeing with most of these statements, you may be leaning toward having surgery.

Reason for having surgery	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
I want a proven strategy for reducing my risk of developing ovarian cancer.					
Being worried about developing ovarian cancer is impacting my quality of life.					
I am more concerned about developing ovarian cancer than I am about the potential consequences of risk-reducing surgery, such as menopausal symptoms, sexual side effects, and increased osteoporosis risk.					
No matter what physical symptoms I may experience after surgery, I am confident I can manage them.					
Risk-reducing surgery will give me peace of mind.					
Risk-reducing surgery will give my loved ones peace of mind.					

Are there any other reasons for having risk-reducing surgery? List them here.

Reasons for Not Having Risk-Reducing Surgery

This guide has discussed a number of reasons why women choose not to have risk-reducing surgery for ovarian cancer. Read through the following statements and decide how closely each one applies to you. Check the most appropriate box for each reason.

Considering your reaction to these statements may help you make a decision. If you find yourself agreeing with most of these statements, you may be leaning away from having surgery.

Reason for not having surgery	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
I prefer to use non-surgical options, such as oral contraceptives and regular surveillance by my doctor, even though their risk-reduction benefit is not as great as that of surgery.					
I am not worried about developing ovarian cancer, or if I am, it is not impacting my quality of life.					
I am more concerned about the potential consequences of risk-reducing surgery, such as menopausal symptoms, sexual side effects, and increased osteoporosis risk, than about my risk of developing ovarian cancer.					
I am not confident about my ability to manage the symptoms of surgical menopause.					
I am concerned about the impact of risk-reducing surgery on my relationship(s) with my spouse or partner and other family members.					
I prefer to delay risk-reducing surgery to a future date.					

Are there any other reasons for not having risk-reducing surgery right now? List them here.

III. Next Steps: Putting It All Together

Has considering all of these issues helped to clarify your decision? Explain.

What else do you need before you can make a decision or implement the decision you've made? List your needs here. Examples might include the following:

- talking with a trained genetics professional again about your family history,
- learning more about the possible effects of risk-reducing surgery
- doing your own research
- talking with other health care professionals
- talking with other women who have had surgery.

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What steps do you plan to take now?

IV. Considering the Opinions of Others

Ultimately this is your decision to make, but you may find it helpful to enlist the help of others, if you have not already done so. Consider sharing this worksheet with them as a basis for discussion.

Who is playing an important role in your decision (your doctor, spouse, partner, other relatives, friends)? List them here, and indicate what you believe their current opinions to be: (1) you should have risk-reducing surgery; (2) you should not have risk-reducing surgery; (3) undecided.

PERSON	Their opinion about the decision (check one)	Reason(s) behind their opinion (if known)
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	
	<input type="checkbox"/> Have surgery <input type="checkbox"/> Don't have surgery <input type="checkbox"/> Undecided	

V. Case Studies

Below are two case studies, based on real women's stories, which resulted in different decisions about risk-reducing surgery. Although each woman is an individual with her own set of unique circumstances, these stories may help you with your own decision-making.

Case #1: A Decision Not to Have Risk-Reducing Surgery

Donna

Age: 40

Family History: Donna's mother was diagnosed with stage IIIc ovarian cancer at age 75 and with breast cancer at age 50; her maternal aunt died of breast cancer in her mid-30s; another maternal aunt is a two-time survivor of breast cancer that occurred before age 50.

Genetic Testing: BRCA1-positive

Donna discovered that she carried the BRCA1 mutation soon after her mother had finished treatment for stage IIIc ovarian cancer. She immediately decided that she would have risk-reducing surgery to protect herself against what she had seen her mother go through. She was extremely concerned that her mother, an otherwise healthy woman who always ate well and exercised, could develop ovarian cancer—and breast cancer, earlier in her life—as a result of a genetic mutation. Donna was determined to avoid the same experience.

As time passed, however, and Donna's mom finished treatment, her initial certainty about having surgery began to weaken. She reasoned that, if she were going to have surgery to prevent ovarian cancer, she also should consider having surgery to prevent breast cancer (mastectomy, or removal of the breasts), since her family history of that disease was even stronger. However, this was not an option she was willing to consider.

In addition, as she investigated the advantages and disadvantages of risk-reducing surgery for ovarian cancer, she began to worry about the effects of surgical menopause—especially because she was only 40 and potentially several years away from experiencing menopause naturally. She feared the physical and even emotional effects that such an early menopause could cause, and she was concerned about the impact on sexual intimacy. Donna also did some of her own research in the medical literature, and she became concerned that there was not enough known about the long-term effects of removing the ovaries before menopause. She went so far as to call some researchers in the field to ask them their opinion on quality-of-life issues after risk-reducing surgery. She also talked to someone close to her age who had undergone the surgery.

Based on her investigation, Donna has decided not to have risk-reducing surgery in the immediate future. While she plans to revisit her decision periodically, she is comfortable with her choice not to undergo a procedure that may impact her quality of life. Instead, she has chosen to undergo regular screening as part of a risk reduction study at a major cancer center with a family risk assessment program. She understands that the ultrasound and CA-125 tests are not perfect, but she likes being followed closely and knowing that she is contributing to research that could one day benefit her children.

Case #2: A Decision to Have Risk-Reducing Surgery

Ann

Age: 43

Family History: Ann's mother and grandmother had been diagnosed with advanced ovarian cancer in their late 40s; her maternal aunt had breast cancer in her early 50s. Ann was in her mid-20s when her mom was diagnosed.

Genetic Testing: BRCA2-positive

Ann was just beginning to start her own family when her mother developed and eventually died of ovarian cancer. She soon found out that her grandmother, who had died of a so-called "stomach cancer," also likely had ovarian cancer. Her mother's sister, with whom she remains close, is a breast cancer survivor.

Given this pattern, Ann decided to undergo genetic testing at age 41 and discovered that she carries a BRCA2 mutation. This fact, combined with the experience of losing her mother at such a young age, made her very interested in the possibility of having risk-reducing surgery. Her daughters were 15 and 13, and she had no plans to have any more children. In fact, she was starting to look forward to getting them through high school and having more time to spend with her husband. They had often talked about how much they wanted to travel once the kids were in college.

For nearly two years, Ann carefully considered her decision whether or not to have risk-reducing surgery. She knew that she wanted to be free of the anxiety she felt over developing ovarian cancer, and she also knew surgery would be the best solution for reducing risk. Seeing her doctor for regular testing, as she was now doing, only seemed to increase her anxiety, not lessen it. At the same time, though, Ann was concerned about the potential effects of surgical menopause. She was already tired from working part-time and raising two children. She was concerned that these effects could disrupt her daily life and her relationship with her husband.

The more time passed, however, the more anxious Ann became over her risk of ovarian cancer—especially because both her mother and grandmother had been diagnosed in their late 40s. In addition, one of her cousins had recently been diagnosed with breast cancer, which made her feel even more anxious. After a number of conversations with her doctor, her husband, and two other women who had undergone surgery, Ann decided to go ahead and have the surgery in the summer, just after her oldest child graduated from high school. She reasoned that she would have her energy back in time to help her daughter pack up and move to college. Summertime was also less demanding at work and her daughters' schedules were much lighter, too.

After having risk-reducing surgery, Ann found that she experienced most of the side effects her doctor had warned her about, including pretty intense hot flashes, fatigue, and vaginal dryness. Because she was prepared for them, however, they were not as distressing as she had imagined. She worked with her doctor to find ways to cope with them. Even more importantly, she felt as if a weight had been lifted off her shoulders. Ann spent less time thinking about ovarian cancer and worrying about whether or not to have surgery. Although she was still concerned about breast cancer risk, she felt comforted by the fact that the surgery also helped to reduce that risk—and that breast cancer was easier to detect at an early stage if it should develop. She finally felt like she could plan for the future without having to look over her shoulder all of the time.